

**DEPARTMENTS OF LABOR, HEALTH AND
HUMAN SERVICES, AND EDUCATION, AND
RELATED AGENCIES APPROPRIATIONS FOR
FISCAL YEAR 2014**

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on some departmental and all nondepartmental witnesses. The statements and letters of those submitting written testimony are as follows:]

DEPARTMENTAL WITNESSES
RAILROAD RETIREMENT BOARD

PREPARED STATEMENT OF MICHAEL S. SCHWARTZ, CHAIRMAN OF THE BOARD; WALTER A. BARROWS, LABOR MEMBER OF THE BOARD; AND JEROME F. KEVER, MANAGEMENT MEMBER OF THE BOARD

Mr. Chairman and members of the committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2014 budget request of \$111,739,000 for our retirement, unemployment and other programs.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. The RRB has also administered special economic recovery payments and extended unemployment benefits under the American Recovery and Reinvestment Act of 2009 (Public Law 111-5) and extended unemployment benefits under the Worker, Homeownership, and Business Assistance Act of 2009 (Public Law 111-92). More recently, we have administered extended unemployment benefits under the Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (Public Law 111-312), the Temporary Payroll Tax Cut Continuation Act of 2011 (Public Law 112-78), the Middle Class Tax Relief and Job Creation Act of 2012 (Public Law 112-96) and the American Taxpayer Relief Act of 2012 (Public Law 112-240).

During fiscal year 2012, the RRB paid \$11.4 billion, net of recoveries, in retirement/survivor benefits to about 573,000 beneficiaries. We also paid \$76 million in net unemployment/sickness insurance benefits to about 26,000 claimants. Temporary extended unemployment benefits paid were \$7.2 million. In addition, the RRB paid benefits on behalf of the Social Security Administration amounting to \$1.4 billion to about 114,000 beneficiaries.

PROPOSED FUNDING FOR AGENCY ADMINISTRATION

The President's proposed budget would provide \$111,739,000 for agency operations, which would enable us to maintain a staffing level of 860 full-time equivalent staff years (FTEs) in 2014. The proposed budget would also provide \$2,860,500 for information technology (IT) investments. This includes \$2,100,000 for the final phase of our system processing for excess earnings data (SPEED) application. The remaining \$760,500 would be used for other technology investments in network op-

erations, and e-Government. In addition, the proposed budget would provide \$600,000 for a Voice over the Internet Protocol system that provides a significant return on investment to our communications infrastructure in the areas of day-to-day operations and cost containment.

AGENCY STAFFING

The RRB's dedicated and experienced workforce is the foundation for our tradition of excellence in customer service and satisfaction. Like many Federal agencies, however, the RRB has a number of employees at or near retirement age. About 65 percent of our employees have 20 or more years of service, and over 36 percent of our current workforce will be eligible for retirement by fiscal year 2014. To help prepare for the expected staff turnover in the near future, we are placing increased emphasis on modernization strategies to convert manual workloads to automated and strategic management of human capital. Our human capital plans provide for employee support and knowledge transfer, which will enable the RRB to continue achieving its mission. In addition, with the agency's formal human capital plan, succession plan and various action plans in place, we are ensuring that succession management supports a systematic approach to ensuring a continuous supply of the best talent through helping individuals develop to their full potential.

In connection with these workforce planning efforts, the President's budget request includes a legislative proposal to enable the RRB to utilize various hiring authorities available to other Federal agencies. Section 7(b)(9) of the Railroad Retirement Act contains language requiring that all employees of the RRB, except for one assistant for each Board Member, must be hired under the competitive civil service. We propose to eliminate this requirement, thereby enabling the RRB to use various hiring authorities offered by the Office of Personnel Management. Also, our budget request includes a legislative proposal to clarify the authority of the Railroad Retirement Board to hire attorneys through competitive civil service.

INFORMATION TECHNOLOGY IMPROVEMENTS

We are actively pursuing further automation and modernization of the RRB's various processing systems to support the agency's mission to administer benefit programs for railroad workers and their families. In fiscal year 2014, funding is included for contractor support to complete the full design of the System Processing Excess Earnings Data (SPEED) application. The SPEED application, started in 2006, is being built in phases to accommodate complex transactions and system interconnections. Once completed, SPEED will automate time consuming and complex manual processing of annuity adjustments resulting from post retirement work/earnings by employee and spouse annuitants. We expect automation of this workload to reduce staffing requirements and reduce improper payments through increased timeliness in handling.

OTHER REQUESTED FUNDING

The President's proposed budget includes \$39 million to fund the continuing phase-out of vested dual benefits, plus a 2 percent contingency reserve, \$780,000, which "shall be available proportional to the amount by which the product of recipients and the average benefit received exceeds the amount available for payment of vested dual benefits." In addition, the President's proposed budget includes \$150,000 for interest related to uncashed railroad retirement checks.

FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—The RRB continues to coordinate its activities with the National Railroad Retirement Investment Trust (Trust), which was established by the Railroad Retirement and Survivors' Improvement Act of 2001 (RRSIA) to manage and invest railroad retirement assets. Pursuant to the RRSIA, the RRB has transferred a total of \$21.276 billion to the Trust. All of these transfers were made in fiscal years 2002 through 2004. The Trust has invested the transferred funds, and the results of these investments are reported to the RRB and posted periodically on the RRB's website. The net asset value of Trust-managed assets on September 30, 2012, was approximately \$23.6 billion, an increase of almost \$1.5 billion from the previous year. Through December 2012, the Trust had transferred approximately \$13.9 billion to the Railroad Retirement Board for payment of railroad retirement benefits.

In June 2012, we released the report on the railroad retirement system required by Sections 15 and 22 of the Railroad Retirement Act of 1974, and Section 502 of the Railroad Retirement Solvency Act of 1983. The 25th Actuarial Valuation ad-

addressed the 75-year period 2011–2085, and included projections of the status of the retirement trust funds under three employment assumptions. These indicated that barring a sudden, unanticipated, large decrease in railroad employment or substantial investment losses, the railroad retirement system would experience no cash flow problems for the next 23 years. Even under the most pessimistic assumption, the cash flow problems would not occur until the year 2035. The report did not recommend any change in the rate of tax imposed by current law on employers and employees.

Railroad Unemployment Insurance Account.—The RRB’s latest annual report on the financial status of the railroad unemployment insurance system was issued in June 2012. The report indicated that even as maximum daily benefit rates rise 44 percent (from \$66 to \$95) from 2011 to 2022, experience-based contribution rates are expected to keep the unemployment insurance system solvent, except for small, short-term cash-flow problems in 2015, under the most pessimistic assumption. However, projections show quick repayment of any loans by the end of fiscal year 2016.

Unemployment levels are the single most significant factor affecting the financial status of the railroad unemployment insurance system. However, the system’s experience-rating provisions, which adjust contribution rates for changing benefit levels, and its surcharge trigger for maintaining a minimum balance, help to ensure financial stability in the event of adverse economic conditions. No financing changes were recommended at this time by the report.

Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

OFFICE OF INSPECTOR GENERAL

PREPARED STATEMENT OF MARTIN J. DICKMAN, INSPECTOR GENERAL

Mr. Chairman and members of the subcommittee: My name is Martin J. Dickman, and I am the Inspector General for the Railroad Retirement Board. I would like to thank you, Mr. Chairman, and the members of the subcommittee for your continued support of the Office of Inspector General.

BUDGET REQUEST

The President’s proposed budget for fiscal year 2014 would provide \$8,877,000 to the Office of Inspector General (OIG) to ensure the continuation of the OIG’s independent oversight of the Railroad Retirement Board (RRB). During fiscal year 2014, the OIG will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste and abuse.

OPERATIONAL COMPONENTS

The OIG has three operational components: the immediate Office of the Inspector General, the Office of Audit (OA), and the Office of Investigations (OI). The OIG conducts operations from several locations: the RRB’s headquarters in Chicago, Illinois; an investigative field office in Philadelphia, Pennsylvania; and five domicile investigative offices located in Virginia, Texas, California, Florida, and New York. These domicile offices provide more effective and efficient coordination with other Inspector General offices and traditional law enforcement agencies, with which the OIG works joint investigations.

OFFICE OF AUDIT

The mission of the Office of Audit is to promote economy, efficiency, and effectiveness in the administration of RRB programs and detect and prevent fraud and abuse in such programs. To accomplish its mission, OA conducts financial, performance, and compliance audits and evaluations of RRB programs. In addition, OA develops the OIG’s response to audit-related requirements and requests for information.

During fiscal year 2014, OA will focus on areas affecting program performance; the efficiency and effectiveness of agency operations; and areas of potential fraud, waste, and abuse. OA will continue its emphasis on long-term systemic problems and solutions, and will address major issues that affect the RRB’s service to rail beneficiaries and their families. OA has identified four broad areas of potential audit coverage: Financial Accountability; Railroad Retirement Act & Railroad Unemployment Insurance Act Benefit Program Operations; Railroad Medicare Program Operations; and Security, Privacy, and Information Management. OA must also ac-

comply with the following mandated activities with its own staff: Audit of the RRB's financial statements pursuant to the requirements of the Accountability of Tax Dollars Act of 2002, evaluation of information security pursuant to the Federal Information Security Management Act (FISMA), and an audit of the RRB's compliance with the Improper Payments Elimination and Recovery Act of 2010.

During fiscal year 2014, OA will complete the audit of the RRB's fiscal year 2013 financial statements and begin its audit of the agency's fiscal year 2014 financial statements. OA contracts with a consulting actuary for technical assistance in auditing the RRB's "Statement of Social Insurance", which became basic financial information effective in fiscal year 2006. In addition to performing the annual evaluation of information security, OA also conducts audits of individual computer application systems which are required to support the annual FISMA evaluation. Our work in this area is targeted toward the identification and elimination of security deficiencies and system vulnerabilities, including controls over sensitive personally identifiable information.

OA undertakes additional projects with the objective of allocating available audit resources to areas in which they will have the greatest value. In making that determination, OA considers staff availability, current trends in management, Congressional and Presidential concerns.

OFFICE OF INVESTIGATIONS

The Office of Investigations (OI) focuses its efforts on identifying, investigating, and presenting cases for prosecution, throughout the United States, concerning fraud in RRB benefit programs. OI conducts investigations relating to the fraudulent receipt of RRB disability, unemployment, sickness, and retirement/survivor benefits. OI investigates railroad employers and unions when there is an indication that they have submitted false reports to the RRB. OI also conducts investigations involving fraudulent claims submitted to the Railroad Medicare Program. These investigative efforts can result in criminal convictions, administrative sanctions, civil penalties, and the recovery of program benefit funds.

OI INVESTIGATIVE RESULTS FOR FISCAL YEAR 2012

Civil Judgments	Indictments/Informations	Convictions	Recoveries/Receivables
26	106	85	¹ \$77,405,487

¹ This total includes the results of joint investigations with other agencies.

OI anticipates an ongoing caseload of about 450 investigations in fiscal year 2014. During fiscal year 2012, OI opened 168 new cases and closed 258. At present, OI has cases open in 48 States, the District of Columbia, and Canada with estimated fraud losses of nearly \$124 million. Disability fraud cases represent the largest portion of OI's total caseload. These cases involve more complicated schemes and often result in the recovery of substantial amounts for the RRB's trust funds. They also require considerable resources such as travel by special agents to conduct surveillance, numerous witness interviews, and more sophisticated investigative techniques. Additionally, these fraud investigations are extremely document-intensive and require forensic financial analysis.

Of particular significance is an ongoing disability fraud investigation in New York. To date, 32 individuals have been indicted (23 have pled guilty), and OI agents will likely have to spend a substantial amount of time traveling to New York for continuing investigations and trial preparation in fiscal year 2014.

During fiscal year 2014, OI will continue to coordinate its efforts with agency program managers to address vulnerabilities in benefit programs that allow fraudulent activity to occur and will recommend changes to ensure program integrity. OI plans to continue proactive projects to identify fraud matters that are not detected through the agency's program policing mechanisms.

CONCLUSION

In fiscal year 2014, the OIG will continue to focus its resources on the review and improvement of RRB operations and will conduct activities to ensure the integrity of the agency's trust funds. This office will continue to work with agency officials to ensure the agency is providing quality service to railroad workers and their families. The OIG will also aggressively pursue all individuals who engage in activities to fraudulently receive RRB funds. The OIG will continue to keep the subcommittee and other members of Congress informed of any agency operational problems or deficiencies. The OIG sincerely appreciates its cooperative relationship with the agen-

cy and the ongoing assistance extended to its staff during the performance of their audits and investigations. Thank you for your consideration.

CORPORATION FOR PUBLIC BROADCASTING

PREPARED STATEMENT OF PATRICIA HARRISON, PRESIDENT AND CEO

Chairman Harkin and distinguished members of the subcommittee, thank you for allowing me to submit this testimony on behalf of America's public media service—public television and public radio—on-air, online and in the community. The Corporation for Public Broadcasting (CPB) requests \$445 million for fiscal year 2016 and \$27.3 million for the Department of Education's Ready To Learn program in fiscal year 2014.

Since 1967, the Corporation for Public Broadcasting has served as the steward of continuing Federal appropriations for public television and radio. Today we are a system comprising more than 1,400 locally owned and locally operated public radio and television stations serving local rural and urban communities throughout the country. More than 98 percent of the American people turn to American public media for high quality content that educates, informs, inspires and entertains. Public media's commitment to early and lifelong learning, available to all citizens, helps strengthen our civil society and our democracy. Our trusted, noncommercial services available for free to all Americans is especially important to those living in rural communities where the local public media station is the only source of broadcast news, information and educational programming.

The financial support for the public broadcasting system that is derived from the Federal appropriation is the essential investment keeping public media free and commercial free for all Americans. Former President Ronald Reagan said, "government should provide the spark and the private sector should do the rest." And what stations do with the spark of Federal dollars, which amounts to approximately 15 percent of a station's budget, results in a uniquely entrepreneurial and American public media system with a track record of proven benefits delivered through stations to the American people.

Federal money is the indispensable foundation upon which stations build and raise, on average, at least six times the amount they receive from the Federal Government. And it is this initial investment in public media that keeps it commercial free and available to all Americans for free. However, smaller stations serving rural, minority and other underserved communities are hard pressed to raise six times the Federal appropriation which can represent 40 percent of their budget. While their communities do the best they can in terms of financial support, the fact is, without the Federal appropriation these stations would cease to exist.

No matter what their size, all public media stations work for, and are accountable to, the people in the communities they serve. That connection is important because as stations acquire national programming, they also produce local content and services based on the needs of their respective communities.

As the steward of these important taxpayer dollars, CPB ensures that 95 cents of every dollar received goes to support local stations and the programs and services they offer to their communities; no more than five cents of every dollar goes to the administration of funding programs and overhead. Approximately 19 percent of CPB's funding is directed to the production or acquisition of programming, making CPB the largest single funder of content for children's programming such as Sesame Street and Daniel Tiger's Neighborhood; for public affairs programming such as PBS NewsHour, Morning Edition and Frontline; and for programming such as Nova, Nature, American Experience, StoryCorps and the films of Ken Burns.

The Public Broadcasting Act ensures diversity in this programming by requiring CPB to fund independent and minority producers. CPB fulfills this obligation, in part, by funding the Independent Television Service, the five Minority Consortia entities in television (which represent African American, Latino, Asian American, Native American and Pacific Islander producers), several public radio consortia (Latino Public Radio Consortia, African American Public Radio Stations, and Native Public Media) and numerous minority public radio stations. In addition, CPB, through its Diversity and Innovation fund, makes direct investments in the development of diverse primetime and children's broadcast programs as well as innovative digital content.

In the past year, CPB provided support for Southern California Public Radio's launch of the "One Nation Media Project," which produces quality, multimedia journalism that engages a general audience while emphasizing topics that resonate authentically with multiethnic communities; the production of America Revisited, a

three-part series by filmmaker Stanley Nelson on the history of African Americans; a documentary called *The Graduates* by filmmaker Bernardo Ruiz, which looks at the education challenges faced by Latino boys and girls; and *PARALYMPICS*, which introduces American audiences to high performing disabled athletes and the biomechanics of disabled sports.

For an investment of approximately \$1.35 per American per year, public broadcasting stations are able to train teachers and help educate America's children in school and at home; provide in-depth journalism that informs citizens about important issues in their neighborhoods, their country, and around the globe; make the arts accessible to all Americans; and provide emergency alert services for their communities.

CORPORATION FOR PUBLIC BROADCASTING

CPB's mission is to facilitate the development of, and ensure universal access to, high-quality noncommercial programming and telecommunications services, and to strengthen and advance public broadcasting's service to the American people. CPB does not own or operate public broadcasting stations, or govern the national public media organizations. As steward of these important funds, we ensure these monies are invested in stations that serve our communities and programs that help strengthen our civil society.

CPB strategically focuses investments through the lens of what we refer to as the "Three D's"—Digital, Diversity and Dialogue. This refers to support for innovation on digital platforms, extending public media's reach and service over multiple platforms; content that is for, by and about Americans of all backgrounds; and services that foster dialogue and a deeper engagement between the American people and the public service media organizations that serve them.

One example of a CPB investment that embodies each of the Three D's is our investment in education. Public broadcasting's contribution to education—from early childhood through adult learning—is well documented. We are America's largest classroom, with proven content available to all children, including those who cannot afford preschool. Our content is repeatedly regarded as "most trusted" by parents, caregivers and teachers. Now, building upon our success in early childhood education, CPB is leading a national initiative to help communities address the high school dropout crisis called, "American Graduate: Let's Make It Happen." More than 75 public media stations located in 33 States with at-risk communities are working with more than 800 national and community-based partners to mobilize and bring together diverse stakeholders and community organizations; filling voids in information, resources and solutions; building and sharing best practices for teacher training and student engagement; creating local programming around the dropout issue unique to their communities, and leveraging digital media and technology to engage students in an effort to keep them on the path to graduation.

CORPORATION FOR PUBLIC BROADCASTING'S REQUEST FOR APPROPRIATIONS

Our fiscal year 2016 request balances the fiscal reality facing our Nation with the bare fact that stations are struggling to provide service to their communities in the face of shrinking non-Federal revenues—a \$239 million, or 10.8 percent, drop between fiscal year 2008 and fiscal year 2011. Even with these challenges, public broadcasting contributes to American society in many ways that are worthy of greater Federal investment. In fiscal year 2016, CPB will continue to support a range of programming and initiatives through which stations provide a valuable and trusted service to millions of Americans.

CPB Base Appropriation (Fiscal Year 2016).—CPB requests a \$445 million advance appropriation for fiscal year 2016, to be spent in accordance with the Public Broadcasting Act's funding formula. The two-year advance appropriation for public broadcasting, in place since 1976, is the most important part of the "firewall" that Congress constructed between Federal funding and the programs that appear on public television and radio. President Gerald Ford, who initially proposed a five-year advance appropriation for CPB, said it best when he said that advance funding "is a constructive approach to the sensitive relationship between Federal funding and freedom of expression. It would eliminate the scrutiny of programming that could be associated with the normal budgetary and appropriations processes of the government."

Ready To Learn (Fiscal Year 2014).—CPB requests that the U.S. Department of Education's Ready To Learn (RTL) program be funded at \$27.3 million, the same level as fiscal year 2013. Mr. Chairman, education is the heart of public media. RTL is a partnership between the Department, CPB, PBS and local public television stations that leverages the power of digital television technology, the Internet, gaming

platforms and other media to help millions of young children learn the reading and math skills they need to succeed in school. The partnership's work over the past few years has demonstrably increased reading scores particularly among low-income children and is helping to erase the performance gap between children from low-income households and their more affluent peers. An appropriation of \$27.3 million in fiscal year 2014 will enable RTL to develop tools to improve children's performance in math as well as reading and bring on-the-ground, station-convened early learning activities to more communities.

All told, the Federal contribution to public media through CPB amounts to \$1.35 per American per year, and the return on investment to the American taxpayer can be measured in the numbers of children now ready to learn in school; through in-depth news and public affairs programming on the local, State, national and international level; unmatched, commercial-free children's programming; formal and informal educational instruction for all ages; or inspiring arts and cultural content.

Americans no longer sit back and experience appointment television or radio. They are on the move and public media is there with them, utilizing today's technology to provide content of value to millions of citizens who trust us to deliver content that matters and is relevant to their lives today.

Mr. Chairman and members of the subcommittee, thank you again for allowing CPB to submit this testimony. On behalf of the public broadcasting community, including the stations in your States and those they serve, we sincerely appreciate your support.

NONDEPARTMENTAL WITNESSES

PREPARED STATEMENT OF THE ACADEMY OF RADIOLOGY RESEARCH

Thank you for providing the Academy of Radiology Research with the opportunity to submit testimony on fiscal year 2014 funding for the National Institutes of Health (NIH). The imaging research community deeply appreciates the subcommittee's leadership in recommending a baseline increase to NIH funding in fiscal year 2013. This represented a much-needed step in the right direction for medical research.

After the sequestration cut of 5.1 percent to the NIH in fiscal year 2013, the final appropriation for the agency will be approximately \$29.3 billion (assuming a relatively flat fiscal year 2013 level). Looking back to fiscal year 2004, NIH funding stood at \$27.8 billion—which means our engine for medical breakthroughs in the U.S. has grown a total of 5.02 percent over the past decade, or at a compounded annualized rate of 0.54 percent. While we acknowledge that the subcommittee is not responsible for the sequester, the annualized growth rate for NIH over the past decade without sequestration (1.01 percent) also does not reflect that of an innovation economy.

NIH Director Francis Collins, M.D., Ph.D., recently stated before the subcommittee on March 5 that other nations are “ramping up their support of biomedical research because they’ve read our playbook.” Indeed, unlike the U.S., both emerging and developed economies continue to prioritize public funding for medical research and development. China alone is committing an average of \$60 billion per year to biotechnology over the next 5 years—double the budget of the NIH. If NIH had continued its historical annual rate of growth (6.5 percent) from the 1960s to 1998 after the “doubling,” it would now be supported at \$46.7 billion a year. Even a smaller but sustainable level of 4 percent annual growth since 2004 would put NIH funding at \$38.5 billion today.

It is also important to note that NIH Directors did not wake up to a –5.1 percent sequester order on March 2, and are just now finding superfluous areas to trim, fat to cut, or duplication to eradicate. Directors and their staff have managed flat budgets, with eroding purchasing power, for the past decade. The sequester reductions are squarely on highly meritorious proposals.

It is time to move NIH back into meaningful positive direction, ensuring that it can sustain and grow the number of multi-year investigator-initiated research grants, the foundation of our Nation's biomedical research enterprise. We ask that the subcommittee prioritize NIH even within the statutorily imposed flat budget caps, and begin reinvigorating medical research.

THE NATIONAL INSTITUTE OF BIOMEDICAL IMAGING AND BIOENGINEERING AS AN INCUBATOR AND SUPPLIER OF NEW TECHNOLOGIES

Since the 1980s, many clinical and technological advances in CT, MRI, PET imaging, and image-guided therapies have been developed through funding from the National Institute for Biomedical Imaging and Bioengineering (NIBIB). Radiology research is truly an interdisciplinary science, bringing together physicians, physicists, mathematicians, chemists, computer scientists, physiologists and others from numerous scientific fields. This strong and diverse research pipeline has helped solidify the U.S. as the world leader in the basic research, development, and commercialization of advanced medical imaging technologies. It also makes the investment in NIBIB's research particularly valuable, as there are three distinct outputs from NIBIB research:

- bench-to-bedside imaging tools that help medical professionals diagnose, treat, and monitor a wide array of diseases and conditions, saving millions of lives each year;
- bench-to-bench interdisciplinary research tools that have given thousands of researchers in other fields game-changing new ways to tackle the diseases that they study; and

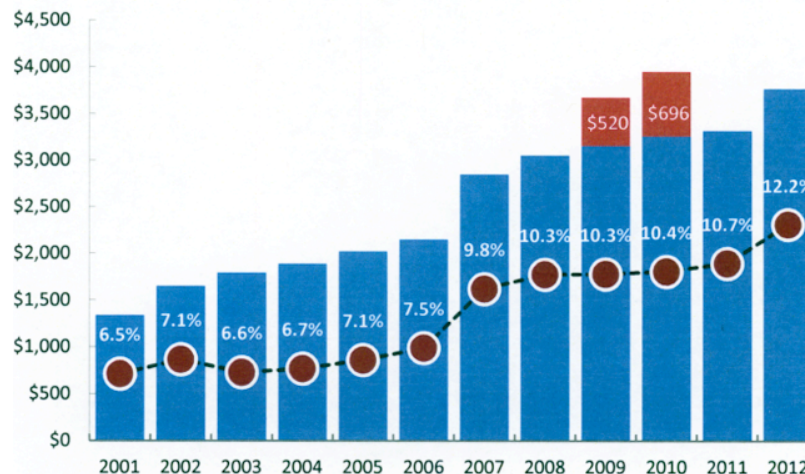
—a pipeline for commercial imaging products, as medical imaging devices represent one of the Nation's healthiest export industries, providing tens of thousands of high-skilled jobs across the country and adding positively to the Nation's gross domestic product.

Imaging Research as a Bench-to-Bedside Tool

One recent NIBIB-funded discovery—magnetic resonance elastography (MR elastography)—highlights just how radiology researchers are constantly pushing the technological envelope to improve human health. It has long been known that diseased tissue has different mechanical properties that surrounding normal tissue. Specifically, it tends to exhibit a slightly more rigid structure as the disease takes over. Previously, the only way to know that this was occurring was after a biopsy, usually late in the disease's progression. However, radiology researchers knew that if they could use advanced imaging to see these slight biomechanical changes in tissue stiffness, patients and fellow physicians would have a powerful new tool to find tumors earlier than ever before.

NIBIB researchers found that by passing MRI waves through diseased tissue—such as a liver tumor—that they could use new algorithms and gradients to quantitatively measure and image the tissue's rigidity or stiffness. This has tremendous clinical implications, as a number of diseases including liver disease, breast cancer, prostate cancer, and many others can be detected at the earliest stages using MR elastography. Patients suspected of liver disease or cancer may think they are getting “an MRI.” However, at places like Mayo Clinic, the radiologists are likely using a new and better imaging test made possible with taxpayer-supported imaging R&D.

TOTAL AMOUNT OF GRANTS USING ADVANCED IMAGING TOOLS PRODUCED BY RADIOLOGY RESEARCH, AND AS A PERCENT OF THE TOTAL NIH BUDGET, 2001–2012



Imaging as a Bench-to-Bench Research Tool

Researchers in nearly every field of study at NIH are taking advantage of imaging tools being developed by NIBIB and radiology researchers, using advanced imaging technologies to improve their understanding of disease and accelerate treatments. Demonstrating the scope of the imaging research “toolkit,” every NIH Institute funded projects that utilized imaging in fiscal year 2011, and nearly half of all Institutes invested 10 percent or more of their budget to imaging projects in fiscal year 2011. Of the 239 NIH Research, Disease and Condition Categorization (RCDC) codes at NIH, imaging projects were funded in 211 (88 percent) of all diseases being studied. The largest funder was the National Cancer Institute (NCI) at \$527 million (10 percent), while other ICs dedicating more than 10 percent of their budget to imaging projects also align with some of the Nation's most pressing health concerns, such as Alzheimer's (NIA—17 percent), neurological disorders and stroke (NINDS—19 percent), and heart disease (NHLBI—12 percent). Across the NIH research enter-

prise, there is a large and sustained consumer demand for new imaging projects being developed by NIBIB researchers.

Imaging Research as a Pipeline for One of America's Strongest Industries

The Department of Commerce identifies medical imaging equipment as one of the country's strongest projected exports for the coming decade. NIBIB research will play a key collaborative role in helping to cement U.S. leadership in the imaging sector by fortifying the pipeline for state-of-the-art imaging equipment. The downstream economic impact from NIBIB research is significant, as GE's MRI division alone supports over 19,000 full-time positions in the U.S., while exporting over 1,000 MRI magnets per year from its MRI manufacturing facility in Florence, South Carolina.

Although relatively small at \$338 million in fiscal year 2012, the NIBIB is especially important as the Federal incubator for innovation in the rapidly moving field of medical imaging. Given its three-legged return on investment as a supplier of new technologies for patient care, a developer of game-changing new technologies for scientists in all fields, and a pipeline for a key domestic sector, we request a shift in the NIH portfolio for greater investment in imaging R&D.

A global benchmark for R&D spending for an innovation economy is 3 percent of GDP. We recommend that the NIH portfolio begin to be readjusted in fiscal year 2014 to allow for this same investment in imaging R&D, increasing the proportion of funding to NIBIB from the current 1.10 percent of the NIH budget to 3.0 percent over the next 5 years. This path to increased imaging R&D would call for a \$70 million increase for NIBIB in fiscal year 2014.

PREPARED STATEMENT OF ACADEMYHEALTH

AcademyHealth is pleased to offer this testimony regarding the role of health services research in improving our Nation's health and the performance of the health care and public health systems. AcademyHealth's mission is to support research that leads to accessible, high value, high-quality health care; reduces disparities; and improves health. We represent the interests of more than 4,400 scientists and policy experts and 160 organizations that produce and use research to improve health and health care. We advocate for the funding to support health services research; a robust environment to produce this research; and its more widespread dissemination and use.

As medical research discovers for cures for disease, health services research discovers cures for the health system. This research diagnoses problems in health care and public health delivery and identifies solutions to improve outcomes for more people, at greater value. This research is used by patients, health care providers, public health professionals, hospitals, employers, and public and private payers to enhance consumer choice, improve patient safety, and promote high quality care.

Finding new ways to get the most out of every health care dollar is critical to our Nation's long-term fiscal health. Like any corporation making sure it is developing and providing high quality products, the Federal Government—as the Nation's largest health care purchaser—has a responsibility to get the most value out of every taxpayer dollar it spends on Medicare, Medicaid, Children's Health Insurance Program, and veterans' and service members' health. Health services research into the merits of different policy options for delivery system transformation, patient-centered quality improvement, community health, and disease prevention offers policymakers in both the public and private sectors the information they need to improve quality and outcomes, identify waste, eliminate fraud, increase efficiency and value, and promote personal choice.

Put plainly, health services research helps Americans get their money's worth when it comes health care. We need more of it, not less. Despite the positive impact health services research has had on the U.S. health care system, and the potential for future improvements in quality and value, the United States spends less than one cent of every health care dollar on this research; research that can help Americans spend their health care dollars more wisely and make more informed health care choices.

We respectfully ask that the subcommittee instead consider the value of health services research and strengthen its capacity to address the pressing challenges America faces in providing access to high-quality, efficient care. The following list summarizes AcademyHealth's fiscal year 2014 funding recommendations for agencies that support health services research and health data under the subcommittee's jurisdiction.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The Agency for Healthcare Research and Quality (AHRQ) is the Federal health services research agency with the sole purpose of improving health care. AHRQ funds health services research and health care improvement programs in universities, medical centers, and research institutions that are transforming people's health in communities in every State around the Nation. The science funded by AHRQ provides consumers and their health care professionals with valuable evidence to make health care decisions. For example, medical societies use AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes and rheumatoid arthritis. These evidence-informed recommendations give physicians a foundation for describing what the best care looks like, so millions of patients living with these and other conditions may determine what the right care might be for them.

AHRQ's research also provides the basis for protocols that prevent medical errors and reduce hospital-acquired infections (HAI), and improve patient experiences and outcomes. For example, AHRQ's evidence-based Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP)—first applied on a large scale in 2003 across more than 100 ICUs across Michigan—saved more than 1,500 lives and nearly \$200 million in the program's first 18 months. The protocols have since been expanded to hospitals in all 50 States, the District of Columbia, and Puerto Rico to continue the national implementation of this approach for reducing HAIs.

AcademyHealth joins the Friends of AHRQ—an alliance of health professional, research, consumer, and employer organizations that support the agency—in recommending an overall funding level of \$434 million for AHRQ in fiscal year 2014, consistent with the President's request.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency. Housed within the Centers for Disease Control and Prevention (CDC), it provides critical data on all aspects of our health care system through data cooperatives and surveys that serve as a gold standard for data collection around the world. AcademyHealth appreciates the subcommittee's support of NCHS in recent years. Such efforts have allowed NCHS to reinstate data collection and quality control efforts, continue the collection of vital statistics, and enhanced the agency's ability to modernize surveys to reflect changes in demography, geography, and health delivery.

We join the Friends of NCHS—an alliance of health professional, research, consumer, industry, and employer organizations that support the agency—in recommending an overall funding level of \$181.5 million for NCHS in fiscal year 2014, consistent with the President's request. This funding will put the agency on track to become a fully functioning, 21st Century, national statistical agency.

NATIONAL INSTITUTES OF HEALTH

NIH spends approximately \$1 billion on health services research annually—roughly 3 percent of its entire budget—making it the largest Federal sponsor of health services research. We join the research community in seeking at least \$32 billion for NIH in fiscal year 2014. NIH has an important role in the Federal health services research continuum, and is well-positioned to ensure that discoveries from clinical trials are effectively translated into health care delivery. AcademyHealth supports efforts to help NIH foster greater coordination of its health services research investment among its institutes and across other Federal agencies to avoid duplication.

AcademyHealth also recommends that the Clinical and Translational Science Awards (CTSA) through the National Center for Advancing Translational Sciences (NCATS) sustain investment in the full spectrum of translational research (T1–T4). The CTSA program enables innovative research teams to speed discovery and advance science aimed at improving our Nation's health. The program encourages collaboration in solving complex health and research challenges and finding ways to turn their discoveries into practical solutions for patients.

CENTERS FOR MEDICARE AND MEDICAID SERVICES

Steady funding decreases for the Office of Research, Development and Information have hindered CMS's ability to meet its statutory requirements and conduct new research to strengthen public insurance programs, which together cover nearly 100 million Americans and comprise 45 percent of America's total health expenditures.

As these Federal entitlement programs continue to pose significant budget challenges for both Federal and State governments, it is critical that we adequately fund research to evaluate the programs' efficiency and effectiveness and seek ways to manage their projected spending growth. AcademyHealth supports CMS's discretionary research and development budget to improve the effectiveness and efficiency of these programs.

In conclusion, the accomplishments of health services research would not be possible without the leadership and support of this subcommittee. We hope the subcommittee gives strong consideration to our fiscal year 2014 funding recommendations for the Federal agencies funding health services research and health data. If you have questions or comments about this testimony or wish to know more about health services research, please contact Lisa Simpson, President and CEO of AcademyHealth, or lisa.simpson@academyhealth.org.

PREPARED STATEMENT OF THE AD HOC GROUP FOR MEDICAL RESEARCH

The Ad Hoc Group for Medical Research is a coalition of more than 300 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry. We appreciate the opportunity to submit this statement in support of enhancing the Federal investment in biomedical, behavioral, and population-based research conducted and supported by the National Institutes of Health (NIH).

We are deeply grateful to the subcommittee for its long-standing and bipartisan leadership in support of NIH. These are difficult times for our Nation and for people all around the globe, but we believe that science and innovation are essential if we are to continue to improve our Nation's health, sustain our leadership in medical research, and remain competitive in today's global information and innovation-based economy. The Ad Hoc Group recommends that NIH receive at least \$32 billion in fiscal year 2014. We believe this amount is the minimum level of funding needed to accommodate the rising costs of medical research and to help mitigate the effects of sequestration. The Ad Hoc Group also encourages the subcommittee to work to stop the pernicious cuts to research funding that squander invaluable scientific opportunities, discourage up and coming scientists, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic vitality.

NIH: A Public-Private Partnership to Save Lives and Provide Hope

The partnership between NIH and America's scientists, medical schools, teaching hospitals, universities, and research institutions is a unique and highly-productive relationship, leveraging the full strength of our Nation's research enterprise to foster discovery, improve our understanding of the underlying cause of disease, and develop the next generation of medical advancements. Approximately 84 percent of the NIH's budget goes to more than 300,000 research positions at over 2,500 universities and research institutions located in every State.

The Federal Government has a unique role in supporting medical research. No other public, corporate or charitable entity is willing or able to provide the broad and sustained funding for the cutting edge basic research necessary to yield new innovations and technologies in the future.

Research funded by NIH has contributed to nearly every medical treatment, diagnostic tool, and medical device developed in modern history, and we all are enjoying longer, healthier lives thanks to the Federal Government's wise investment in this lifesaving agency. From the major advances—including a nearly 70 percent reduction in the death rate for coronary heart disease and stroke—to moving stories of personalized medicine—such as children with rare diseases like dopa-responsive dystopia, whose prognosis has been transformed from severely disabled to happy and healthy through genomic medicine—NIH's role in improving human health has been extraordinary. NIH research impacts the full spectrum of the human experience, resulting in a 40 percent decline in infant mortality over the past 20 years, as well as a 30 percent decrease in chronic disability among seniors. For patients and their families, NIH is the "National Institutes of Hope."

NIH is the world's premiere supporter of merit-reviewed, investigator-initiated basic research. This fundamental understanding of how disease works and insight into the cellular, molecular, and genetic processes underlying life itself, including the impact of social environment on these processes, underpin our ability to conquer devastating illnesses. The application of the results of basic research to the detection, diagnosis, treatment, and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also sup-

porting the translational efforts necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

The research supported by NIH drives not only medical progress but also local and national economic activity, creating skilled, high-paying jobs and fostering new products and industries. According to a report released by United for Medical Research, a coalition of scientific advocates, institutions and industries, in fiscal year 2011, NIH-funded research supported an estimated 432,000 jobs all across the United States, enabled 13 States to experience job growth of more than 10,000 jobs, and generated more than \$62 billion in new economic activity. Another report, produced by Tripp Umbach, calculated a \$2.60 return on investment for every public dollar spent on research at American medical schools and teaching hospitals.

Sequestration Threatens Scientific Momentum

As patients, health care providers, and scientists we are deeply disturbed about the impact the more than 5 percent cut in NIH funding under sequestration in the current fiscal year will have on our ability to sustain the scientific momentum that has contributed so greatly to our Nation's health and our economic vitality. But sequestration represents only the latest threat to the viability of this Nation's medical research enterprise, following a decade when NIH has lost nearly one-fifth of its buying power after inflation.

The leadership and staff at NIH and its Institutes and Centers has engaged patient groups, scientific societies, and research institutions to identify emerging research opportunities and urgent health needs, and has worked resolutely to prioritize precious Federal dollars to those areas demonstrating the greatest promise. But a continued erosion of our national commitment to medical research threatens our ability to support a medical research enterprise that is capable of taking full advantage of existing and emerging scientific opportunities.

Perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. NIH also plays a significant role in supporting the next generation of innovators, the young and talented scientists and physicians who will be responsible for the breakthroughs of tomorrow. Appearing before the House Labor-HHS-Education Appropriations Subcommittee on March 5, NIH Director Francis Collins, M.D., Ph.D., said, "That's our seed corn. It has been the strength of America . . . the biomedical research community, their creativity, their innovative instincts, and we're putting that at serious risk as we see this kind of downturn in the support for research."

The challenges of maintaining a cadre of physician-scientists to facilitate translation of basic research to human medicine, ensuring a biomedical workforce that reflects the racial and gender diversity of our citizenry, and maximizing our Nation's human capital to solve our most pressing health problems will only be addressed through continued support of NIH.

NIH is Critical to U.S. Competitiveness

Our country still has the most robust medical research capacity in the world, but that capacity simply cannot weather repeated blows such as persistent below-inflation funding levels and cuts of sequestration, which jeopardize our competitive edge in an increasingly innovation-based global marketplace. Dr. Collins testified earlier this year that other nations are "ramping up their support of biomedical research because they've read our playbook." A 2012 report from the Information Technology and Innovation Foundation stated, "China, for example, has identified biotechnology as one of seven key strategic and emerging (SEI) pillar industries and has pledged to invest \$308.5 billion in biotechnology over the next 5 years. This means that, if current trends in biomedical research investment continue, the U.S. Government's investment in life sciences research over the ensuing half-decade is likely to be barely half that of China's in current dollars, and roughly one-quarter of China's level as a share of GDP Other countries are also investing more in biomedical research relative to the sizes of their economies. When it comes to Government funding for pharmaceutical industry-performed research, Korea's government provides seven times more funding as a share of GDP than does the United States, while Singapore and Taiwan provide five and three times as much, respectively."

Talented medical researchers from all over the world, who once flocked to the U.S. for training and stayed to contribute to our innovation-driven economy, are now returning to better opportunities in their home countries. We cannot afford to lose that intellectual capacity, much less the jobs and industries fueled by medical research. The U.S. has been the global leader in medical research because of Congress's bipartisan recognition of NIH's critical role. To maintain our dominance,

we must reaffirm this commitment to provide NIH the funds needed to maintain our competitive edge.

NIH: An Answer to Challenging Times

The Ad Hoc Group's members recognize the tremendous challenges facing our Nation's economy and acknowledge the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe strongly that NIH is an essential part of the solution to the Nation's economic restoration. Strengthening our commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

Therefore, the Ad Hoc Group for Medical Research respectfully requests that the subcommittee recognize NIH as an urgent national priority and provide at least \$32 billion in the fiscal year 2014 appropriations bill.

PREPARED STATEMENT OF THE AIDS HEALTHCARE FOUNDATION

Dear Mr. Chairman Harkin and Ranking Member Moran: My name is Tom Myers, and I am the General Counsel for the AIDS Healthcare Foundation (AHF). AHF hereby submits the following testimony and funding request in the amount of \$2,422,178,000 for the Ryan White CARE Act for fiscal year 2014:

Consistent with goal number 4 of the National HIV/AIDS Strategy for the United States—"Achieving a More Coordinated Response to the HIV Epidemic in the United States"—appropriations for the Ryan White CARE Act (the "CARE Act") in fiscal year 2014 presents a unique opportunity to harmonize the CARE Act with the Strategy's three main goals:

- Reducing New HIV Infections;
- Increasing Access to Care and Improving Health Outcomes for People Living With HIV; and
- Reducing HIV-Related Health Disparities.

Funding of the CARE Act at the requested level will allow the CARE Act to be harmonized with the changes in health care delivery to be brought about by the Affordable Care Act ("ACA") to provide a more comprehensive and more effective response to the HIV epidemic in the U.S.

The current state and trends of the HIV/AIDS epidemic in the United States should guide how to harmonize the CARE Act with Health Care Reform and the National HIV/AIDS Strategy.

While the future is always uncertain, and it is unclear exactly what the consequences of the ACA will be, there are a number of facts that can help determine necessary funding for the CARE Act:

- There will be a need for a robust CARE Act, in its current form, for the foreseeable future.*—The implementation of Medicaid expansion and insurance exchanges will be neither a quick nor complete process. Full-scale change is not set to begin until 2014, and even now, many States, including those with some of the largest HIV/AIDS populations such as Texas and Georgia—are delaying or foregoing participating in Medicaid expansion or setting up exchanges. As a result, the safety net that is the CARE Act will need to remain largely intact until this process is complete, and will need to be available for those States the do not fully implement the ACA.
- Most Americans with HIV are not linked to or retained in HIV care.*—Many American still do not know their HIV status, are not linked to HIV care, and are not retained in HIV care. In fact, a minority of all Americans with HIV are on antiretroviral treatment. Supporting access to and maintenance of care will be critical to ending the epidemic.
- Neither Medicaid nor insurance exchanges may provide all the services currently available under the CARE Act.*—The CARE Act understands that effectively treating a complex, chronic disease like HIV requires a number of approaches, disciplines, and services. Insurance plans and Medicaid, in both of which people living with HIV area small minority of participants, may not be organized with the needs of people living with HIV in mind, and may not offer the full range of services provided by the CARE Act.
- 20 percent of Americans with HIV are unaware of their status.*—This group is thought unwittingly to be the source of 70 percent of all new infections. The HIV epidemic in the United States will not end until this group is made aware of their status, and are brought into care.
- Treatment is Prevention.*—One of the consensus emerging from the recent International AIDS Conference is that HIV treatment, which can reduce the

chances of infection by up to 96 percent, is the most effective and the most cost effective way to prevent new infections. Getting people living with HIV into care, and keeping them adherent to treatment, will be the key to ending this epidemic.

—*The HIV Epidemic in the U.S. continues to trend South, and in Communities of Color.*—Recent publications have documented and highlighted the enormous disparities in HIV rates and new infections in the South, and among communities of color. Addressing these disparities, in many States that have expressed a reluctance to implement the ACA, will be paramount in fighting the epidemic.

Given the above facts, in order to ensure that adequate care, treatment and prevention services are available to fully combat the HIV/AIDS epidemic in the United States, funding the Care Act at the requested level is required. Thank you for your attention and support in this matter. We look forward to working with you to ensure that the CARE Act continues to be part of an effective, comprehensive program to end HIV/AIDS in America.

PREPARED STATEMENT OF THE AIDS INSTITUTE

Dear Chairman Harkin and members of the subcommittee: My name is Carl Schmid, Deputy Executive Director of the AIDS Institute. The AIDS Institute, a national public policy, research, advocacy, and education organization, is pleased to offer comments in support of critical HIV/AIDS programs as part of the fiscal year 2014 Labor, Health and Human Services, Education, and Related Agencies appropriation measure. We thank you for supporting these programs over the years, and hope you will do your best to adequately fund them in the future in order to provide for and protect the health of many Americans.

HIV/AIDS remains one of the world's worst health pandemics. According to the CDC, in the U.S. over 636,000 people have died of AIDS and there are 50,000 new infections each year. A record 1.2 million people in the U.S. are living with HIV. Persons of minority races and ethnicities are disproportionately affected. African Americans, who make up just 12 percent of the population, account for 44 percent of the new infections. HIV/AIDS disproportionately affects low income people; nearly 90 percent of Ryan White Program clients have a household income of less than 200 percent of the Federal Poverty Level.

The U.S. Government has played a leading role in fighting HIV/AIDS, both here and abroad. The vast majority of the discretionary programs supporting domestic HIV/AIDS efforts are funded through this subcommittee. We are keenly aware of current budget constraints and competing interests for limited dollars, but programs that prevent and treat HIV are inherently in the Federal interest as they protect the public health against a highly infectious virus. If left unaddressed it will certainly lead to increased infections, more deaths, and higher health costs.

With the advent of antiretroviral medicines, HIV has turned from a near certain death sentence to a treatable chronic disease if people have access to consistent and affordable health care and medications. Through prevention, care and treatment, and research we now have the ability to actually end AIDS. In 2011, a groundbreaking clinical trial (HPTN 052)—named the scientific breakthrough of the year by Science magazine—found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96 percent—proving that HIV treatment is also HIV prevention. In order to realize these benefits, people with HIV must be diagnosed through testing, linked to and retained in care and treatment.

We also have a National HIV/AIDS Strategy that sets clear goals and priorities, and brings all the Federal agencies addressing HIV together to ensure Federal resources are well coordinated.

With all these positive developments it would be a shame to go backwards, but that is what could happen given the sequestration and budget cuts that are impacting the Ryan White Program at HRSA, HIV and Hepatitis prevention programs at the CDC, and research at the NIH.

The Ryan White HIV/AIDS Program

The Ryan White HIV/AIDS Program provides some level of medical care, drug treatment, and support services to approximately 546,000 low-income, uninsured, and underinsured individuals with HIV/AIDS. With people living longer and continued new diagnoses, the demands on the program continue to grow and many needs remain unmet. According to the CDC, only 37 percent of people living with HIV in the U.S. are retained in HIV care, only 33 percent have been prescribed antiretroviral treatment, and only 25 percent are virally suppressed. We have a long

way to go before we can realize the dream of an AIDS-free generation. With continued funding we can reverse these trends.

The AIDS Drug Assistance Program (ADAP), one component of the Ryan White Program, provides States with funds to pay for medications for over 200,000 people. Over the last couple of years, as more infections were identified due to increased HIV testing and people lost their jobs and health insurance, demand on the program far outpaced its budget. This led to ADAP wait lists of 9,300 people. We are thankful that President Obama and Congress allocated additional funds, which when combined with assistance from pharmaceutical companies reduced the wait lists to less than 50 people today.

This could all change because \$35 million transferred by President Obama on World AIDS Day 2011 for ADAP was not continued in the fiscal year 2013 Continuing Resolution. While we are hopeful the President will transfer some of this funding again, it is critical that the \$35 million be maintained in fiscal year 2014. If it is not, an estimated 8,000 patients currently taking medications through ADAP will risk losing access to their lifesaving medications. This would be very dangerous as once antiretroviral treatment begins, the drugs must be taken every day without interruption or resistance to medications will occur.

On top of this loss of funding, sequestration has reduced current ADAP funding by another \$45 million. The loss of this funding could force States to stop paying for medications to another 14,000 people currently taking medications. We urge you to do all you can to prevent this and ensure ADAP and the rest of the Ryan White Program receive adequate funding to keep up with the growing demand. According to NASTAD, enrollment in ADAP increased last year by 13,500 people, or 8 percent. While it will be not sufficient, we are pleased the President has requested an increase of \$10 million to ADAP in fiscal year 2014 for a total of \$943.3 million.

With this increased demand for medications comes a corresponding increase in medical care and support services provided by all other parts of the program. Sequestration will be reducing these services by over \$70 million in 2013. We urge the Committee to restore these harmful cuts and ensure the entire Ryan White Program is adequately funded in fiscal year 2014.

We are looking forward to implementation of the expanded opportunities for health care coverage under the Affordable Care Act (ACA). While it will result in some cost shifting for medications and primary care, it will never be a substitute for the Ryan White Program. Over 70 percent of Ryan White Program clients today have some sort of insurance coverage, mostly through traditional Medicaid and Medicare. Their coverage will not change with health reform; the Ryan White Program will be needed as it is today for coverage completion services. The Medicaid expansion is a State option and about half of the States are not moving forward with it at this time. As ACA is implemented, benefits will differ from State to State and there will be many gaps that will have to be filled by the Ryan White Program. Plans will not offer all comprehensive essential support services, such as case management, transportation, and nutritional services, that are needed to ensure retention in medical care and adherence to drug treatment. For example, Part D of the Ryan White Program provides family-centered care to women, infants, children, and youth living with HIV/AIDS. This approach of coordinated, comprehensive, and culturally competent care leads to better health outcomes. Therefore, the Ryan White Program, while it may need to change in the future, must continue and must be adequately funded.

CDC HIV Prevention

As a Nation, we must do more to prevent new HIV infections, but we only allocate 3 percent of our HIV/AIDS spending towards prevention. All the care and treatments costs would be saved if we did not have the infections in the first place. Preventing just one infection would save \$355,000 in future lifetime medical costs. Preventing all the new 50,000 cases in just 1 year would translate into an astounding \$18 billion saved in lifetime medical costs.

With more people living with HIV than ever before, there are greater chances of HIV transmission. The CDC and its grantees have been doing their best with limited resources to keep the number of infections stable, but that is not good enough. It is focusing resources on those populations and communities most impacted by HIV and investing in those programs that will prevent the most number of infections. This means more of its resources will be going to the South and focusing on gay men. One group in particular that needs additional study and resources is young black gay men, who experienced a 38 percent increase in new infections from 2008–2010.

With over 200,000 people living with HIV who are unaware of their infection, the CDC is also focused on increased testing programs. Testing people early and linking

them to care and treatment is critical not only for their own health outcomes but also in preventing new infections. It is estimated that sequestration would reduce the annual number of HIV tests by 424,000.

The CDC estimates that in 2010, 26 percent of all new HIV infections occurred among youth ages 13 to 24. Nearly 75 percent of those infections were among young gay men. Clearly, we must do a better job of educating the youth of our Nation, including gay youth, about HIV. To compound matters, the HIV Division of Adolescent and School Health (DASH) lost 25 percent of its budget in fiscal year 2012. We ask that the subcommittee restore this \$10 million cut.

For the first year of sequestration, CDC's HIV prevention programs will be cut by over \$40 million, which will put at risk all the recent progress we are making in reducing the number of new infections.

The President has proposed to replace the sequester and increase CDC's HIV prevention programs by \$10 million in fiscal year 2014. Additionally, he has proposed redirecting some current HIV testing funding to assist State health departments and others to develop billing systems for HIV testing. The AIDS Institute supports this initiative so that States and others can take advantage of the coverage of preventive services under the Affordable Care Act.

HIV/AIDS Research at the National Institutes of Health (NIH)

While we have made great strides in the area of HIV/AIDS, there is still a long way to go. Continued research at the NIH is necessary to learn more about the disease and to develop new treatments and prevention tools. Work continues on vaccine research and we look forward to an eventual cure. Sequestration will mean loss of \$163 million in HIV/AIDS research funding, and 297 HIV/AIDS research grants would go unfunded.

Viral Hepatitis

There are over 5.3 million people in the U.S. infected with viral hepatitis, and seventy-five percent are not aware of their infection, yet hepatitis prevention at the CDC is funded at only \$30 million. This is insufficient to provide basic public health services such as education, counseling and testing. Increased funding is needed to implement the HHS Viral Hepatitis Action Plan and the strategy in the Institute of Medicine (IOM) report, *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*.

The AIDS Institute urges the Federal Government to make a greater commitment to Hepatitis prevention. For fiscal year 2014, we request an increase of at least \$6 million for a total of \$36.6 million.

Policy Riders

The AIDS Institute is opposed to using the appropriations process as a vehicle to repeal or prevent the implementation of current law or ban funding for certain activities or organizations. This includes implementation of the Affordable Care Act. We also urge you not to interfere with the implementation of programs, such as syringe exchange programs, which are scientifically proven to be effective in the prevention of HIV and Hepatitis.

Again, we thank you for your continued support of these critical programs important to so many individuals and communities nationwide. We have made great progress, but we are still far from achieving our goal of an AIDS-free generation. We now have the tools, but we need continued leadership and the necessary resources to realize our goal. Thank you.

PREPARED STATEMENT OF AIDS UNITED

On behalf of AIDS United and our diverse partner organizations I am pleased to submit this testimony to the Members of this subcommittee on the urgency of needed funding for the fiscal year 2014 domestic HIV/AIDS portfolio. AIDS United is a national organization that seeks to end the AIDS epidemic in the United States by combining private-sector fundraising, philanthropy, coalition building, public policy expertise, and advocacy—as well as a network of passionate local and State partners—to respond effectively and efficiently to the HIV/AIDS epidemic in the communities most impacted by the epidemic. Through its unique Public/Private Partnerships, Public Policy Committee and targeted special grant-making initiatives, AIDS United represents over 300 grassroots organizations. These organizations provide HIV prevention, care, treatment, and support services to underserved individuals and populations most impacted by the HIV/AIDS epidemic including communities of color, women and gay and bisexual men and men who have sex with men (MSM) as well as education and training to providers of treatment services.

AIDS United understands the fiscal environment that the country is wrestling with right now is austere. However, we know that investment in prevention and retention in HIV care are critical in lowering the number of new infections in the domestic HIV epidemic. As competing budget priorities are weighed please keep in mind that HIV is 100 percent preventable, if we as a Nation muster up the political will and funding to address domestic HIV on level that meets the needs of the epidemic.

I write to request increased funding for the domestic HIV/AIDS portfolio in fiscal year 2014 to help reach the National HIV/AIDS Strategy (NHAS) vision: "The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life extending care, free from stigma and discrimination." To reach this vision, NHAS states three primary goals on which we must focus our efforts.

The first NHAS goal calls for: "Reducing the number of people who become infected with HIV." To continue progress in achieving this goal, the Centers for Disease Control and Prevention's (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (Center) needs to be funded at the HIV/AIDS community's request of \$1.460 billion to ensure that prevention messages can be targeted to reach hard to reach populations who do not believe they are vulnerable to HIV infection as well as the approximately 20 percent of HIV positive individuals who are unaware of their HIV status. President Obama's fiscal year 2014 request for the Center is an increase of \$71.3 million (including the Working Capital Fund); AIDS United feels this is the minimum amount that must be incorporated this year in order to reach the high impact prevention targets the CDC has developed. According to the CDC, the estimated return on investment for CDC dollars spent has been 350,000 HIV infections averted and \$125 billion in direct medical costs saved. Preventing an HIV infection is less costly than treating HIV disease.

AIDS United draws the subcommittee's attention to an important HIV prevention policy issue that does not require direct funding. We urge the sub-committee to include syringe access language that was enacted into law in fiscal year 2010 and fiscal year 2011. Unfortunately, fiscal year 2012 restored an obsolete rider that bans the use of Federal funds for syringe exchange despite clear evidence that syringe exchange programs reduce HIV and hepatitis C infections and reduce substance abuse as well. The fiscal year 2011 language states that Federal funding may be used for syringe exchange programs unless local public health or local law enforcement authorities deem a site to be "inappropriate." This language best ensures authentic local control and lets local communities make their own decisions about how best to prevent new HIV and hepatitis infections. Sixteen percent of HIV/AIDS cases and more than 55 percent of hepatitis C cases are directly or indirectly related to injection drug use. Numerous studies have shown that syringe exchange programs are a cost-effective means to lower rates of HIV/AIDS and viral hepatitis, reduce the use of illegal drugs and help connect people to medical treatment, including substance abuse treatment.

"Increasing access to care and optimizing health outcomes for people living with HIV" is the second NHAS primary goal. The CDC estimates that 1.2 million people are living with HIV in the United States. All of these individuals need to have access to care, but since HIV disease is often a disease of poverty many HIV positive individuals are uninsured or underinsured. The Ryan White CARE Act will continue to play a critical role for some of our Nation's most vulnerable citizen's even after full implementation of the Affordable Care Act (ACA) by ensuring coverage completion, addressing gaps in care, ensuring affordability of care, and the provision of HIV services to those left out of reform. In short it will be needed to continue in its role as the payer of last resort for more than 600,000 individuals, both while People Living with HIV/AIDS move into new coverage eligibility over the next years of ACA implementation and afterwards. In fact approximately 75 percent of those served by Ryan White Programs have access to some type of health insurance, but continue to count on essential care and financial support services that only the Ryan White Program provides

The implementation of the ACA will begin in January of 2014, 3 months after the beginning of fiscal year 2014 and current and ongoing investments in the Ryan White Program are essential to ensure that the U.S. builds on the experience of Ryan White Program providers in helping find people living with HIV, linking them to care and ensuring effective treatment, saving lives and eventually helping to end the HIV/AIDS epidemic. By law most Ryan White Program grantees must use 75 percent or more of their funds to provide "core medical services" including medication. The remaining funding is used by grantees to provide services that can help to ensure people living with HIV are able to access, be retained and adhere to reg-

ular treatment and care. There will continue to be a strong need to provide these services critical to good outcomes across the HIV “treatment cascade” not covered or inadequately covered by Medicaid expansion or plans in State and Federal health insurance marketplaces. In fact data shows that 70 percent of clients who receive Ryan White Program funded care reach viral suppression as opposed to just 28 percent of the overall population.

It remains crucial that the Ryan White Program get a substantial increase from this subcommittee. The community believes an increase of \$442.6 million is needed to address all parts of the program, but the Ryan White program must receive at least the President’s fiscal year 2014 requested increase of \$186.5 million.

Another important component of the Ryan White Program that is important for increasing access to care is the AIDS Drug Assistance Program (ADAP). ADAP provides medications for treating people with HIV who cannot access Medicaid or private health insurance. ADAP is able to assist with co-pays for individuals as well. While the waiting list is not large at this time, ADAP is in a continual State of flux. The World AIDS Day funding that President Obama included in fiscal year 2012 ADAP and Part C funding did not transition to the base for the Continuing Resolution for fiscal year 2013. The community is working with the Administration on this fix, but this funding must be included in the base for fiscal year 2014 to ensure those on medication can continue their medications. While we acknowledge the President’s request for an increase of \$92 million for ADAP, AIDS United urges the subcommittee to provide a fiscal year 2014 increase of at least \$214.7 million for this vital, life-saving program.

Addressing workforce issues is important to achieving the goal of increasing access to care and improving health outcomes. The AIDS Education and Training Centers (AETCs), a component of Part F of the Ryan White Program, supports workforce development and training for doctors, advanced practice nurses, physicians’ assistants, nurses, oral health professionals, and pharmacists about HIV treatment, HIV testing, viral hepatitis, and other HIV co-morbidities. AIDS United urges the subcommittee to provide a total of \$42.2 million for Ryan White Part F/AETCs, an increase of \$5.3 million over the fiscal year 2013 funding level.

The third NHAS goal calls for reducing HIV-related health disparities. Racial and ethnic communities continue to be impacted disproportionately and at alarming rates. The impact on black women and gay and bisexual men of color is particularly disturbing. The Minority HIV/AIDS Initiative (MAI) benefits African American, Latino, Asian and Pacific Islander, and Native American and Alaska Native communities across the country. It is essential that the MAI be fully funded in fiscal year 2014 at \$610 million.

The Social Innovation Fund (SIF) administered by the Corporation for National and Community Service, leverages Federal and private resources to support innovative community-based programs that work in improving economic opportunity and healthy futures. SIF funded sites across the country have used \$95 million in Federal investments to leverage \$250 million of additional private support. AIDS United partners are using SIF to expand access to care, improve individual health outcomes, and strengthen local service systems to connect marginalized individuals living with HIV to high quality supportive services and health care. AIDS United urges the subcommittee to provide a total of \$49 million for SIF, consistent with the Administration request.

AmeriCorps, also administered by the Corporation for National and Community Services, provides opportunities for over 70,000 individuals to make an intensive commitment to community service to meet critical needs in education, public safety, and health. Participants in AIDS United’s AmeriCorps Program deliver vital HIV-related services and resources while training the next generation of HIV/AIDS leaders. AIDS United urges the subcommittee to meet the Administration request of \$346 million for fiscal year 2014 funding level for the AmeriCorps State and national programs.

After nearly 32 years, the HIV epidemic is a continuing crisis in the United States. Progress that has been made, however, has enabled more and more people to speak of an end of AIDS in America. We can achieve that by expanding resources for domestic HIV prevention, care and treatment, and research efforts to meet the goals of the National HIV/AIDS Strategy. On behalf of its partner organizations and the many thousands of HIV positive Americans and those affected by HIV who they serve, AIDS United, urges the subcommittee to consider and support the fiscal year 2014 funding levels that we have outlined.

PREPARED STATEMENT OF ALLIANCE FOR AGING RESEARCH

Chairman Harkin, Ranking Member Moran, and members of the subcommittee: My name is Cynthia A. Bens, Vice President of Public Policy for Alliance for Aging Research. For more than 25 years, the not-for-profit Alliance for Aging Research, www.agingresearch.org, has advocated for medical research to improve the quality of life and health for all Americans as we grow older. Our efforts have included supporting increased Federal funding of aging research by the National Institutes of Health (NIH), through the National Institute on Aging (NIA) and other NIH institutes and centers. The Alliance appreciates the opportunity to submit testimony highlighting the important role that the NIH plays in facilitating aging-related medical research activities and the ever more urgent need for sustained Federal investment and focus to advance scientific discoveries to keep individuals healthier longer.

The Alliance for Aging Research supports funding the NIH at \$32 billion in fiscal year 2014 with a minimum of \$1.4 billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging.

The National Institute on Aging (NIA) at NIH leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults. Congress established the NIA in 1974 to conduct research on aging processes, age-related diseases, and special problems and needs of the aged; train and develop research scientists; provide research resources; and disseminate information on health and research advances. NIA is also the primary Federal agency on Alzheimer's disease research. The NIA has been at the forefront of some of the most important advances in aging research and translational programs, including:

- Development of the drug-eluting coronary stent, used to open arterial blockages in the heart during angioplasty. Nearly two million people worldwide have received these stents, which reduce subsequent narrowing rates to three to 6 percent.
- The NIA's Diabetes Prevention Program demonstrated that diet and exercise were the most effective ways to reduce the risk of diabetes in high-risk older people. The clinical trial intervention showed a 71 percent reduction in diabetes among participants 60 and older.
- Karlene Ball, an NIA grantee, developed Useful Field of View (UFOV), which is the area where someone can extract visual information at a glance without head or eye movements. Research found that training UFOV can prospectively reduce automobile crash rates by half. Several State Motor Vehicle Departments are using and testing UFOV, and Allstate Insurance Company and State Farm offer discounts with this training.
- NIA-funded research led by Mary Tinetti, M.D., of the Yale University School of Medicine found that training clinical staff in falls prevention practices and strategies can help reduce serious falls by 9 percent and the need for related medical care by 11 percent among seniors aged 70 and older, reducing the incidence and cost of hospitalizations.
- Researchers from the Alzheimer's Disease Neuroimaging Initiative showed that changes in the levels of certain proteins in cerebrospinal fluid may correlate with the risk and progression of Alzheimer's disease. These biomarkers may be used in the future to identify individuals at risk of developing the disease. In addition, measuring amyloid in the brain may prove promising as a diagnostic tool.
- NIA-funded clinical trials REACH I and REACH II developed and tested strategies for helping caregivers manage the stress and emotional burden of caring for people with dementia. The first study showed a significant improvement in caregivers' sense of burden, social support, depression and health, as well as in care recipients' behavior problems and mood. The U.S. Department of Veterans Affairs successfully used REACH strategies in a demonstration project with 19 of its Home Based Primary Care programs, which treat frail individuals with dementia and caregivers in their homes, and it is now considering using REACH throughout its system. Additionally, the REACH OUT program at the Administration on Aging is beginning to implement these strategies through local social service agencies.

Research toward healthier aging has never been more critical for so many Americans. Older Americans now make up the fastest growing segment of the population. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million, or 20 percent of the population, and those 85 and older will increase three-fold, to 19 million. Diseases such as type 2 diabetes, cancer, neurological diseases, heart disease, and osteoporosis

that largely occur late in life are increasingly driving the need for healthcare services in this country. Many other dreaded diseases of aging like Alzheimer's disease are expected to become more prevalent as the number of older Americans increases. We believe that preventing, treating or curing diseases of aging is perhaps the single most effective strategy available to reduce national spending on health care.

Consider that the average 75-year old has three chronic health conditions and takes five prescription medications. Six diseases—heart disease, stroke, cancer, diabetes, Alzheimer's and Parkinson's diseases—cost the U.S. over \$1 trillion each year. The number of Americans age 65 and older with Alzheimer's disease is projected to more than double over the next 17 years. Cancer incidence is projected to increase by about 45 percent between 2010–2030, largely because of cancer diagnoses in older Americans and minorities. By 2030, people aged 65 and older will represent 70 percent of all cancer diagnoses in the U.S.

The rising tide of chronic diseases of aging threatens to overwhelm the U.S. health care system in the coming years. Research which leads to a better understanding of the aging process and human vulnerability to age-related diseases could be the key to helping Americans live longer, more productive lives, and simultaneously reduce the need for care to manage costly chronic diseases. Scientists who study aging now generally agree that aging is malleable and capable of being slowed. Rapid progress in recent years toward understanding and making use of this malleability has paved the way for breakthroughs that could increase human health in later life by opposing the primary risk factor for virtually every disease we face as we grow older—aging itself. Better understating of this “common denominator” of disease could usher in a new era of preventive medicine, enabling interventions that stave off everything from dementia to cancer to osteoporosis. As we now confront unprecedented aging of our population and staggering increases in chronic age-related diseases and disabilities, a modest extensions of healthy lifespan could produce outsized returns of extended productivity, reduced caregiver burdens, lessened Medicare spending, and more effective healthcare in future years.

The NIA leads national research efforts within the NIH to better understand the aging process and ways to better maintain the health and independence of Americans as they age. NIA is poised to accelerate the scientific discoveries. The science of aging is showing increasing power to address the leading public health challenges of our time. Leaders in the biology of aging believe it is now realistically possible to develop interventions that slow the aging process and greatly reduce the risk of many diseases and disabilities, including cancer, diabetes, Alzheimer's disease, vision loss and bone and joint disorders. While there has been great progress in aging research, a large gap remains between promising basic research and healthcare applications. Closing that gap will require considerable focus and investment. Key aging processes have been identified by leading scientists as potentially yielding crucial answers in the next 3–10 years. These include stress response at the cellular level, cell turnover and repair mechanisms, and inflammation.

A central theme in modern aging research—perhaps its key insight—is that the mutations, diets, and drugs that extend lifespan in laboratory animals by slowing aging often increase the resistance of cells, and animals, to toxic agents and other forms of stress. These discoveries have two main implications, each of which is likely to lead to major advances in anti-aging science in the near future. First is the suggestion that stress resistance may itself be the facilitator (rather than merely the companion) of the exceptional lifespan in these animal models, hinting that studies of agents that modulate resistance to stress could be a potent source of valuable clinical leverage and preventive medicines. Second is the observation that the mutations that slow aging augment resistance to multiple varieties of stress—not just oxidation, or radiation damage, or heavy metal toxins, but rather resistance to all of these at the same time.

The implication is that cells have “master switches,” which, like rheostats that can brighten or dim all lights in a room, can tweak a wide range of protective intracellular circuits to tune the rate of aging differently in long-lived versus short-lived individuals and species. If this is correct, research aimed at identifying these master switches, and fine-tuning them in ways that slow aging without unwanted side-effects, could effectively postpone all of the physiological disorders of aging through manipulation of the aging rate itself. Researchers have formulated, and are beginning to pursue, new ways to test these concepts by analysis of invertebrates, cells lines, laboratory animals and humans, and by comparing animals of species that age more quickly or slowly.

One hallmark of aging tissues is their reduced ability to regenerate and repair. Many tissues are replenished by stem cells. In some aged tissues, stem cell numbers drop. In others, the number of stem cells changes very little—but they malfunction. Little is currently known about these stem cell declines, but one suspected cause

is the accumulation of “senescent” cells. Cellular senescence stops damaged or distressed cells from dividing, which protects against cancer. At advanced ages, however, the accumulation of senescent cells may limit regeneration and repair, a phenomenon that has raised many questions. Do senescent cells, for instance, alter tissue “microenvironments,” such that the tissue loses its regenerative powers or paradoxically fuel the lethal proliferation of cancer cells? A robust research initiative on these issues promises to illuminate the roots of a broad range of diseases and disabling conditions, such as osteoporosis, the loss of lean muscle mass with age, and the age-related degeneration of joints and spinal discs. The research is also essential for the development of stem cell therapies, the promise of which has generated much public excitement in recent years. This is because implanting stem cells to renew damaged tissues in older people may not succeed without a better understanding of why such cells lose vitality with age. Importantly, research in this area would also help determine whether interventions that enhance cellular proliferative powers would pose an unacceptable cancer risk.

Acute inflammation is necessary for protection from invading pathogens or foreign bodies and the healing of wounds, but as we age many of us experience chronic, low-level inflammation. Such insidious inflammation is thought to be a major driver of fatal diseases of aging, including cancer, heart disease, and Alzheimer’s disease, as well as of osteoporosis, loss of lean muscle mass after middle age, anemia in the elderly, and cognitive decline after 70. Just about everything that goes wrong with our bodies as we age appears to have an important inflammatory component, and low-level inflammation may well be a significant contributor to the overall aging process itself. As the underlying mechanisms of age-related inflammation are better understood, researchers should be able to identify interventions that can safely curtail its deleterious effects beginning in mid-life, broadly enhancing later-life, and with negligible risk of side effects.

While important advances have been made toward understanding how aging is linked to disease in an effort to add healthy years to life, such a goal cannot be achieved in a timely way without financial support. An increase in funding for aging research is urgently needed to enable scientists to capitalize on the field’s recent exciting discoveries. For the past year and a half, the Alliance for Aging Research, has led the Healthspan Campaign—an awareness campaign to educate the public and policymakers about the need to focus and adequately fund basic research into the underlying processes of aging—that if targeted can extend a person’s healthy years of life. In addition to increased resources, we believed that the field could benefit from the creation of a trans-NIH initiative that could improve the quality and pace of research that advances the understanding aging, its impact on age-related diseases, and the development of interventions to extend human healthspan. Throughout the first half of 2012 the Alliance and its Healthspan Campaign partners met with leadership of the National Institute on Aging (NIA), the National Institute of Neurological Diseases and Stroke (NINDS), the National Institute of Arthritis Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK), the National Heart Lung and Blood Institute (NHLBI), and the National Cancer Institute (NCI). As a result of this advocacy, in less than 6 months the NIA—through its Division of Aging Biology—took the lead in establishing a Geroscience Interest Group (GSIG) to coordinate discussion and action across the NIH on understanding the role aging plays in our susceptibility to age-related diseases. Of the 27 Institutes and Centers that make up the NIH, 20 are now members of the GSIG—making it the top interest group at the NIH.

The GSIG was written up in the March/April 2012 issue of “The NIH Catalyst,” the NIH’s intramural research newsletter, and Dr. Felipe Sierra, NIA Division of Aging Biology Director and GSIG Coordinator, was awarded an NIH Director’s award for his groundbreaking work with the GSIG. The work of the GSIG was recognized in report language in the fiscal year 2013 Senate Labor, Health and Human Services (LHHS) Appropriations bill. To date the GSIG has held four educational seminars on topics ranging from age-dependent mechanisms in Alzheimer’s and Parkinson’s diseases to insights on aging from Hutchinson-Gilford Progeria Syndrome. The group convened a major workshop on inflammation and aging in the fall of 2012 that resulted in a meaningful joint funding proposal across several NIH institutes. Planning is now underway for a larger and more impactful meeting in fall of 2013 on multiple processes of aging and disease. This meeting will produce many other promising priority areas for further collaboration.

The field of aging research is poised to make transformational gains in the near future but we can only capitalize on this potential if the NIH is properly resourced across institutes and centers. Few if any areas for investing research dollars offer greater potential returns for public health. The Alliance for Aging Research supports funding the NIH at \$32 billion in fiscal year 2014 with a minimum of \$1.4

billion in funding for the NIA specifically. This level of support would allow the NIH and the NIA to adequately fund new and existing research projects, accelerating progress toward findings which could prevent, treat, slow the progression or even possibly cure conditions related to aging. With a tsunami of age driven chronic ailments looming as our population grows older, an increased emphasis on NIH's aging research activities has never been more urgent, with potential to impact so many Americans.

Therapies that delay aging would lessen our healthcare system's dependence on a strategy of trying to address diseases of aging one at a time, often after it is too late for meaningful benefit. They would also address the fact that while advances in lowering mortality from heart attack and stroke have dramatically increased life expectancy, they have left us vulnerable to other age-related diseases and disorders that develop in parallel, such as Alzheimer's disease, diabetes, and frailty. Properly focused and funded research could benefit millions of people by adding active, healthy, and productive years to life. Furthermore, the research will provide insights into the causes of and strategies for reducing the periods of disability that generally occur at the end of life.

Mr. Chairman, the Alliance for Aging Research thanks you for the opportunity to outline the challenges posed by the aging population that lie ahead as you consider the fiscal year 2014 appropriations for the NIH and we would be happy to furnish additional information upon request.

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

The Alzheimer's Association appreciates the opportunity to comment on the fiscal year 2014 appropriations for Alzheimer's disease research, education, outreach and support at the U.S. Department of Health and Human Services.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease and other dementias through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. As the world's largest non-profit funder of Alzheimer's research, the Association is committed to accelerating progress of new treatments, preventions and, ultimately, a cure. Through our funded projects and partnerships, we have been part of every major research advancement over the past 30 years. Likewise, the Association works to enhance care and provide support for all those affected by Alzheimer's and reaches millions of people affected by Alzheimer's and their caregivers.

Alzheimer's Impact on the American People and the Economy

In addition to the human suffering caused by the disease, Alzheimer's is creating an enormous strain on the health care system, families and the Federal budget. Alzheimer's is a progressive brain disorder that damages and eventually destroys brain cells, leading to a loss of memory, thinking and other brain functions. Ultimately, Alzheimer's is fatal. Currently, Alzheimer's is the sixth leading cause of death in the United States and the only one of the top ten without a means to prevent, cure or slow its progression. Over 5 million Americans are living with Alzheimer's, with 200,000 under the age of 65.

A Federal commitment can lower costs and improve health outcomes for people living with Alzheimer's today and in the future. By making Alzheimer's a national priority, we can create the same successes that we have been able to achieve in other diseases that have been prioritized by the Federal Government. Leadership from the Federal Government has helped to lower the number of deaths from other major diseases like heart disease, HIV/AIDS, many cancers, heart disease and stroke. While those deaths have declined, deaths from Alzheimer's have increased 68 percent between 2000 and 2010.

Alzheimer's is the most expensive disease in America. In fact, an NIH-funded study in the New England Journal of Medicine confirmed that Alzheimer's is the most costly disease in America, with costs set to skyrocket at unprecedented rates. In 2013, America is estimated to spend \$203 billion in direct costs for those with Alzheimer's, including \$142 billion in costs to Medicare and Medicaid. Average per person Medicare costs for those with Alzheimer's and other dementias are three times higher than those without these conditions. Average per senior Medicaid spending is 19 times higher. A primary reason for these high costs is that Alzheimer's makes treating other diseases more expensive, as most individuals with Alzheimer's have one or more co-morbidities that complicate the management of the

condition(s) and increases costs. For example, a senior with diabetes and Alzheimer's costs Medicare 81 percent more than a senior who only has diabetes.

If nothing is done, as many as 16 million Americans will have Alzheimer's disease by 2050 and costs will exceed \$1.2 trillion (not adjusted for inflation), creating an enormous strain on the healthcare system, families and the Federal budget. The expense involved in caring for those with Alzheimer's is not just a long-term problem. As the current generation of baby boomers age, near-term costs for caring for those with Alzheimer's will balloon, as Medicare and Medicaid will cover more than two-thirds of the costs for their care.

With Alzheimer's, it is not just those with the disease who suffer—it is also their caregivers and families. In 2012, 15.4 million family members and friends provided unpaid care valued at over \$216 billion. Caring for a person with Alzheimer's takes longer, lasts longer, is more personal and intrusive, and takes a heavy toll on the health of the caregivers themselves. More than 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, with one-third reporting symptoms of depression. Caregiving also has a negative impact on health, employment, income and finances for countless American families. Due to the physical and emotional toll of caregiving on their own health, Alzheimer's and dementia caregivers had \$9.1 billion in additional health costs in 2012.

Changing the Trajectory of Alzheimer's

Until recently, there was no Federal Government strategy to address this looming crisis. In 2010, thanks to bipartisan support in Congress, the National Alzheimer's Project Act (NAPA) (Public Law 111–375) passed unanimously, requiring the creation of an annually-updated strategic National Alzheimer's Plan (Plan) to help those with the disease and their families today and to change the trajectory of the disease for the future. The Plan is required to include an evaluation of all federally-funded efforts in Alzheimer's research, care and services—along with their outcomes. In addition, the Plan must outline priority actions to reduce the financial impact of Alzheimer's on Federal programs and on families; improve health outcomes for all Americans living with Alzheimer's; and improve the prevention, diagnosis, treatment, care, institutional-, home-, and community-based Alzheimer's programs for individuals with Alzheimer's and their caregivers. NAPA will allow Congress to assess whether the Nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA will, for the first time, enable Congress and the American people to answer this simple question: Did we make satisfactory progress this past year in the fight against Alzheimer's?

As mandated by NAPA, the Secretary of Health and Human Services, in collaboration with the Advisory Council on Alzheimer's Research, Care and Services, developed the first-ever National Plan to Address Alzheimer's Disease in May of 2012. The Advisory Council, composed of both Federal members and expert non-Federal members, is an integral part of the planning process as it advises the Secretary in developing and evaluating the annual Plan, makes recommendations to the Secretary and Congress, and assists in coordinating the work of Federal agencies involved in Alzheimer's research, care, and services.

Having this Plan with measurable outcomes is important. But unless there are resources to implement the Plan and the will to abide by it, we cannot hope to make much progress. If we are going to succeed in the fight against Alzheimer's, Congress must provide the resources the scientists need. Understanding this, the President's fiscal year 2014 budget request included \$80 million for research activities at the National Institutes of Health (NIH) and \$20 million for education, outreach, and caregiver support services at the Department of Health and Human Services (HHS). These funds are a critically needed down payment for research and services for Alzheimer's patients and their families.

A disease-modifying or preventive therapy would not only save millions of lives but would save billions of dollars in health care costs. Specifically, a treatment that delayed the onset of Alzheimer's by 5 years (a treatment similar to anti-cholesterol drugs), would reduce Medicare and Medicaid spending nearly in half in 2050.

Today, despite the Federal investment in Alzheimer's research, we are only just beginning to understand what causes the disease. Americans are growing increasingly concerned that we still lack effective treatments that will slow, stop, or cure the disease, and that the pace of progress in developing breakthrough discoveries is much too slow to significantly impact this growing crisis. For every \$29,000 Medicare and Medicaid spend caring for individuals with Alzheimer's, the National Institutes of Health (NIH) spends only \$100 on Alzheimer's research. Scientists fundamentally believe that we have the ideas, the technology and the will to develop new Alzheimer's interventions, but that progress depends on a prioritized scientific

agenda and on the resources necessary to carry out the scientific strategy for both discovery and translation for therapeutic development.

Additional funding is in the NIH budget because their scientists have determined that additional research on Alzheimer's is a priority. Their budget request reflects the changing needs of the Alzheimer's community and the scientific opportunity. It is vital that Congress support the research projects the scientists at NIH deem necessary.

However, Congress does have a responsibility to direct resources to solve the most serious problems. By every objective standard (whether cost to Medicare/Medicaid, families caring for individuals with Alzheimer's, or mortality rate), Alzheimer's is one of our most serious health problems—and it will only get worse as the Baby Boomer generation ages.

Alzheimer's is the most expensive disease in the country not just because of the lack of adequate treatments, but also because our care systems do not effectively address dementia and its consequences. For too many individuals with Alzheimer's and their families, the system has failed them, and today we are unnecessarily losing the battle against this devastating disease. Despite the fact that an early and documented formal diagnosis allows individuals to participate in their own care planning, manage other chronic conditions, participate in clinical trials, and ultimately alleviate the burden on themselves and their loved ones, as many as half of the more than 5 million Americans with Alzheimer's have never received a formal diagnosis. Unless we create an effective, dementia-capable system that finds new solutions to providing high quality care, provides community support services and programs, and addresses Alzheimer's health disparities, Alzheimer's will overwhelm the health care system in the coming years. For example, people with Alzheimer's and other dementias have more than three times as many hospital stays as other older people. Furthermore, one out of seven individuals with Alzheimer's or another dementia lives alone and up to half of them do not have an identifiable caregiver. These individuals are more likely to need emergency medical services because of self-neglect or injury, and are found to be placed into nursing homes earlier, on average, than others with dementia. Ultimately, supporting individuals with Alzheimer's disease and their families and caregivers requires giving them the tools they need to plan for the future and ensuring the best quality of life for individuals and families affected by the disease.

For all these reasons, it is vital that we make the investments in Alzheimer's that were laid out in the President's fiscal year 2014 budget. The President's budget requested \$100 million for research and support services because the needs of the Alzheimer's community have grown. The Alzheimer's Association urges Congress to support the President's budget request of \$100 million for research, education, outreach and support activities and the priorities included in the National Alzheimer's Plan required under Public Law 111–375.

Additional Alzheimer's programs

National Alzheimer's Call Center.—The National Alzheimer's Call Center, funded by the AoA, provides 24/7, year-round telephone support, crisis counseling, care consultation, and information and referral services in 140 languages for persons with Alzheimer's, their family members and informal caregivers. Trained professional staff and master's-level mental health professionals are available at all times. In the 12 month period ending July 31, 2011, the Call Center handled over 300,000 calls through its national and local partners, and its online message board received over 40,000 visits a month. Additionally, the Association provides a two-to-one match on the Federal dollars received for the call center. The Alzheimer's Association urges Congress to support \$1.3 million for the National Alzheimer's Call Center.

Healthy Brain Initiative (HBI).—The Centers for Disease Control and Prevention's (CDC) HBI program works to educate the public, the public health community and health professionals about Alzheimer's as a public health issue. Although there are currently no treatments to delay or stop the deterioration of brain cells caused by Alzheimer's, evidence suggests that preventing or controlling cardiovascular risk factors may benefit brain health. In light of the dramatic aging of the population, scientific advancements in risk behaviors, and the growing awareness of the significant health, social and economic burdens associated with cognitive decline, the Federal commitment to a public health response to this challenge is imperative. The fiscal year 2013 Senate Labor-HHS bill included report language commending HBI for its leadership in bringing attention to the public health crisis of Alzheimer's disease and for its work on cognitive impairment data collection in 45 States, the District of Columbia and Puerto Rico. Additionally, the committee noted that developing a population-based surveillance system with longitudinal follow-up is a key recommendation in the National Public Road Map to Maintaining Cognitive Health,

which was developed jointly by the CDC and the Alzheimer's Association. The bill increased funding for HBI by \$10 million in order to further develop this system and to develop effective public health messages to promote cognitive health in older adults. The Alzheimer's Association urges Congress to support \$11.8 million for the Healthy Brain Initiative.

Alzheimer's Disease Supportive Services Program (ADSSP).—The ADSSP at the AoA supports family caregivers who provide countless hours of unpaid care, thereby enabling their family members with Alzheimer's and dementia to continue living in the community. The program develops coordinated, responsive and innovative community-based support service systems for individuals and families affected by Alzheimer's. The Alzheimer's Association urges Congress to support \$13.4 million for the Alzheimer's Disease Supportive Services Program as recommended by the Advisory Council on Alzheimer's Research, Care and Services.

CONCLUSION

The Association appreciates the steadfast support of the subcommittee and its priority setting activities. We look forward to continuing to work with Congress in order to address the Alzheimer's crisis. Alzheimer's is the costliest disease in the country and these costs are set to increase like for none other. It is vital that Congress supports the President's fiscal year 2014 budget request of an additional \$100 million for Alzheimer's research, education, outreach and support activities to implement the National Alzheimer's Plan. We ask Congress to address Alzheimer's with the same bipartisan collaboration demonstrated in the passage of the National Alzheimer's Project Act (Public Law 111-375) and with a commitment equal to the scale of the crisis.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The American Academy of Family Physicians (AAFP), representing 110,600 family physicians and medical students nationwide, urges the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education to invest in our Nation's primary care physician workforce in the fiscal year 2014 appropriations bill to promote the efficient, effective delivery of health care by providing these appropriations for the Health Resources and Services Administration and the Agency for Healthcare Research and Quality:

- At least \$71 million for Health Professions Primary Care Training and Enhancement authorized under Title VII, Section 747 of the Public Health Service Act (PHSA);
- \$10 million for Teaching Health Centers development grants (PHSA Title VII, § 749A);
- \$4 million for Rural Physician Training Grants (PHSA Title VII, § 749B);
- \$122.2 million for the Office of Rural Health Programs (PHSA §§ 301, 330A, & 338J and §§ 711 and 1820(j), Title XVIII of the Social Security Act (SSA));
- At least \$305 million for the National Health Service Corps (PHSA § 338A, B, & I);
- \$120 million for the Primary Care Extension program (PHSA § 399V-1);
- \$3 million for the National Health Care Workforce Commission (ACA § 5101); and
- \$434 million for the Agency for Healthcare Research and Quality (PHSA § 487(d)(3), SSA § 1142).

The AAFP is one of the Nation's largest medical organizations, representing family physicians, family medicine residents, and medical students nationwide. Founded in 1947, our mission is to preserve and promote the science and art of family medicine and to ensure high-quality, cost-effective health care for patients of all ages.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

Our Nation faces a shortage of primary care physicians. The total number of office visits to primary care physicians is projected to increase from 462 million in 2008 to 565 million in 2025 requiring nearly 52,000 additional primary care physicians by 2025.¹ HRSA is the Federal agency charged with administering the health professions training programs authorized under Title VII of the Public Health Services Act and first enacted in 1963. We urge the Committee to provide at least \$7 billion for HRSA in the fiscal year 2014 appropriations bill.

¹ Petterson, S, et al. Projecting US Primary Care Physician Workforce Needs: 2010–2015. Ann Fam Med 2012; vol.10 no. 6:503–509.

Title VII Health Professions Training Programs.—In the last 50 years, Congress has revised the Title VII authority in order to meet our Nation’s changing health care workforce needs. As the only medical specialty society devoted entirely to primary care, the AAFP is gravely concerned that a failure to provide adequate funding for the Title VII, Section 747 Primary Care Training and Enhancement (PCTE) program, will destabilize education and training support for family physicians. Between 1998 and 2008, in spite of persistent primary care physician shortages, family medicine lost 46 training programs and 390 residency positions, and general internal medicine lost nearly 900 positions.² A study published in the *Annals of Family Medicine* on the impact of Title VII training programs found that physicians who work with the underserved in Community Health Centers and National Health Service Corps sites are more likely to have trained in Title VII-funded programs.³ Title VII primary care training grants are vital to departments of family medicine, general internal medicine, and general pediatrics; they strengthen curricula; and they offer incentives for training in underserved areas. In the coming years, medical services utilization is likely to rise given the increasing and aging population as well as the insured status of more people. These demographic trends will worsen family physician shortages. The AAFP urges the Committee to increase the level of Federal funding for primary care training to at least \$71 million in fiscal year 2014 to support the continuing work of grantees and allow for a new grant cycle.

Teaching Health Centers.—The AAFP has long called for reforms to graduate medical education programs to encourage the training of primary care residents in non-hospital settings where most primary care is delivered. An excellent first step is the innovative Teaching Health Centers program authorized under Title VII, §749A to increase primary care physician training capacity now administered by HRSA. Federal financing of graduate medical education has led to training mainly in hospital inpatient settings even though most patient care is delivered outside of hospitals in ambulatory settings. The Teaching Health Center program provides resources to any qualified community based ambulatory care setting that operates a primary care residency. We believe that this program requires an investment of \$10 million in fiscal year 2014 for planning grants.

Rural Health Needs.—HRSA’s Office of Rural Health focuses on key rural health policy issues and administers targeted rural grant programs. As the medical specialty most likely to enter rural practice, family physicians recognize the need to dedicate resources to rural health needs. A recent study found that medical school rural programs (RPs) have had a significant impact on rural family physician supply and called for wider adoption of that model to substantially increase access to care in rural areas compared with greater reliance on international medical graduates or unfocused expansion of traditional medical schools.⁴ HRSA’s Rural Physician Training Grant program will help medical schools recruit students most likely to practice medicine in rural communities. This program will help provide rural-focused experience and increase the number of medical school graduates who practice in underserved rural communities. The AAFP recommends that the Committee provide \$4 million for Rural Physician Training Grants in fiscal year 2014.

Primary Care in Underserved Areas.—The National Health Service Corps (NHSC) recruits and places medical professionals in Health Professional Shortage Areas to meet the need for health care in rural and medically underserved areas. The NHSC provides scholarships or loan repayment as incentives for physicians to enter primary care and provide health care to Americans in Health Professional Shortage Areas. By addressing medical school debt burdens, the NHSC also helps to ensure wider access to medical education opportunities. The AAFP recommends that the Committee provide at least the mandatory funding of \$305 million for the NHSC in fiscal year 2014.

The AAFP has worked closely with HRSA to promote data-driven community health center expansion. The mapping tool developed and managed by the Robert Graham Center for Policy Studies in Family Practice and Primary Care identifies areas in greatest need for federally Qualified Health Centers. Since the launch of the tool on July 1, 2010, the UDS Mapper has registered over 4,500 users and can be found at <http://www.udsmapper.org/about.cfm>.

² Phillips RL and Turner, BJ. The Next Phase of Title VII Funding for Training Primary Care Physicians for America’s Health Care Needs. *Ann Fam Med* 2012; vol.10 no. 2:163–168.

³ Rittenhouse DR, et al. Impact of Title VII training programs on community health center staffing and national health service corps participation. *Ann Fam Med* 2008; vol. 6 no. 5:397–405.

⁴ Rabinowitz, HK, et al. Medical School Rural Programs: A Comparison With International Medical Graduates in Addressing State-Level Rural Family Physician and Primary Care Supply. *Academic Medicine*, Vol. 87, No. 4/April 2012.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

The mission of the Agency for Healthcare Research and Quality (AHRQ)—to improve the quality, safety, efficiency, and effectiveness of health care for all Americans—closely mirrors AAFP's own mission. AHRQ provides the critical evidence reviews that the AAFP and other physician specialty societies use to produce clinical practice guidelines. AHRQ promotes evidence-based patient safety practices. In addition, AHRQ takes research results from NIH where they restrict research subjects to limit the variables in clinical research and brings the practical information to the practicing physicians who treat patients without those clinical restrictions. AHRQ provides patient-centered health research which improves health care quality by providing patients and physicians with state-of-the-science information on which medical treatments work best for a given condition. The AAFP asks that the Committee provide at least \$434 million for AHRQ in fiscal year 2014.

Primary Care Extension Program.—The AAFP supports AHRQ's Primary Care Extension Program to provide assistance to primary care physicians about evidence-based therapies and techniques so that they can incorporate them into their practice. As AHRQ develops more scientific evidence on best practices and effective clinical innovations, the Primary Care Extension Program will disseminate the information learned to primary care practices across the Nation in much the same way as the Federal Cooperative Extension Service provides small farms with the most current agricultural information and guidance. The AAFP recommends that the Committee provide \$120 million for the AHRQ Primary Care Extension program in fiscal year 2014.

NATIONAL HEALTH CARE WORKFORCE COMMISSION

Appointed on September 30, 2010, the 15-member National Health Care Workforce Commission was intended to serve as a resource with a broad array of expertise. The Commission was directed to analyze current workforce distribution and needs; evaluate health care education and training; identify barriers to improved coordination at the Federal, State, and local levels and recommend ways to address them; and encourage innovations. There is broad consensus about the waning availability of primary care physicians in the United States, but estimates of the severity of the regional and local shortages vary. The AAFP supports the work of the Commission to analyze primary care shortages and propose innovations to help produce the physicians that our Nation needs and will need in the future. We request that the Committee provide \$3 million in fiscal year 2014 so that this important Commission can begin this important work.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF OPHTHALMOLOGY

EXECUTIVE SUMMARY

The American Academy of Ophthalmology requests fiscal year 2014 NIH funding of \$32 billion, which reflects a \$1.38 billion, or 4.5 percent increase, over fiscal year 2012, which consists of biomedical inflation of 2.8 percent plus modest growth. This recommendation reflects the minimum investment necessary to make up for the 20 percent loss in purchasing power over the last decade, as well as the impact of the sequester, which cut 5.1 percent or \$1.6 billion from NIH's \$30.8 billion fiscal year 2013 budget.

NIH, our Nation's biomedical research enterprise, is unique in that:

- Its basic and clinical research has helped to understand the basis of disease, thereby resulting in innovations in healthcare to save and improve lives.
- Its research serves an irreplaceable role the private sector could not duplicate.
- It has been shown through several studies to be a major force in the economic health of communities across the Nation. The latest United for Medical Research report estimates that NIH funding supported more than 432,000 jobs in 2011, directly or indirectly, and generated more than \$62.1 billion in economic activity.

The Academy requests National Eye Institute (NEI) funding at \$730 million, commensurate with the overall NIH funding increase. The President's budget proposes an fiscal year 2014 NEI funding reduction of \$2.1 million to a level \$699 million which is unacceptable since:

- It cuts 35 competing grants. The \$36 million cut in fiscal year 2013 NEI funding due to the sequester has already translated into a loss of an estimated 90 grants—any one of which holds the promise to save or restore vision.

- The cut jeopardizes NEI’s ability to fund new and compelling scientific ideas to advance research, which were identified through its Audacious Goals Initiative.
- Funding at \$699 million is little more than 1 percent of the \$68 billion annual cost of eye disease/vision impairment in the U.S. With the majority of the 78 million Baby Boomers turning 65 years of age this decade and facing the greatest risk of aging eye disease, a cut jeopardizes NEI’s ability to meet the vision challenges presented by this “Silver Tsunami.”

Congress Must Improve Upon the President’s Fiscal Year 2014 Request, Since It Cuts NEI Funding by \$2.1 Million, or 0.3 Percent Below Fiscal Year 2012, Reducing It by \$8 Million Below Its Base Fiscal Year 2010 Level

Despite the President’s request increasing NIH funding by \$471 million, or 1.5 percent, over the fiscal year 2012 level of \$30.6 billion (net of transfers), it proposes to cut NEI by \$2.1 million, or 0.3 percent, below its fiscal year 2012 level of \$701.3 million (net of transfers). Although the cut is primarily driven by an \$8.9 million reduction due to the conclusion of the NEI-sponsored Ocular Complications of AIDS (SOCA) studies which are funded by the NIH Office of AIDS Research, it is still a cut and drives NEI funding in the wrong direction. The President’s proposed fiscal year 2014 NEI funding level of \$699 million falls \$8 million below the base fiscal year 2010 level of \$707 million, the highest NEI funding level ever prior to the addition of American Recovery and Reinvestment Act (ARRA) funding.

Most importantly, the President’s proposed fiscal year 2014 NEI cut of \$2.1 million comes after the fiscal year 2013 sequester cut of \$36 million. The President’s fiscal year 2014 budget would cut 35 competing grants from NEI funding, which follows the sequester’s cut of an estimated 90 grants in fiscal year 2013—any one of which may hold the promise to save or restore vision.

NEI is already facing enormous challenges this decade: each day, from 2011 to 2029, 10,000 citizens will turn 65 and be at greatest risk for eye disease; the African American and Hispanic populations are experiencing a disproportionately higher incidence of eye disease; and the epidemic of obesity is significantly increasing the incidence of diabetic retinopathy and diabetic macular edema. In 2009, Congress spoke volumes in passing S. Res. 209 and H. Res. 366, which designated 2010–2020 as The Decade of Vision. With the fiscal year 2014 LHHHS spending bill, Congress can act upon its past resolutions regarding vision and assure that NEI is adequately funded to meet these challenges.

The Academy also requests NEI funding at \$730 million since our Nation’s investment in vision health is an investment in overall health. NEI’s breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

The very health of the vision research community is also at stake with a decrease in NEI funding. Not only will funding for new investigators be at risk, but also that of seasoned investigators, which threatens the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding. If an institution needs to let staff go, that usually means a highly-trained person is lost to another area of research or an institution in another State, or even another country.

The proposed reduction in NEI funding threatens the United States’ leadership in biomedical research in general, and vision research, specifically.

\$730 Million Fiscal Year 2014 Funding Enables NEI To Pursue Audacious Goals in Vision Research

The NEI is in the middle of a novel planning initiative to identify long-term, 10-year goals in vision research. Under the auspices of the National Advisory Eye Council, this expansion of NEI program planning is designed to engage and energize the vision research community and help the NEI establish the most compelling research priorities by identifying one or more “audacious goals.” Most recently, NEI hosted 200 representatives from every sector of the vision community, as well as Government scientists and regulators from various disciplines at the NEI’s Audacious Goals Development meeting. NIH Director Francis Collins, M.D., Ph.D., was very enthusiastic about this initiative and urged the attendees to have a “bold vision for vision” by describing NEI’s long tradition of leading in the biomedical research arena, including:

- identifying more than 500 genes associated with vision loss, which is one-quarter of all genes discovered to date; and

—funding the successful human gene therapy trial for patients with Leber Congenital Amaurosis, in which treated patients have experienced vision improvement.

The meeting's discussion topics were built around the 10 winning submissions from a pool of nearly 500 entries selected through NEI's Audacious Goals in Vision Research and Blindness Rehabilitation Challenge, a competition for bold and novel ideas to dramatically advance vision science. These ideas included restoring light sensitivity to the blind through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants. Translating these and other research ideas into safe and effective treatments to save and restore vision requires adequate funding.

As a result of past funding, the NEI has made great strides in determining the genetic basis of age-related macular degeneration (AMD)—the leading cause of blindness and a disease for which very little could be done just a few short years ago. NEI's AMD Gene Consortium, a network of international investigators, has just discovered seven new regions of the human genome—called loci—that are associated with increased risk of AMD. They also confirmed 12 loci already identified in previous studies. These loci implicate a variety of biological functions, including regulation of the immune system, maintenance of cellular structure, growth and permeability of blood vessels, lipid metabolism, and atherosclerosis. By understanding the genetic basis of the disease and underlying disease mechanisms, NEI can develop appropriate diagnostic and therapies.

As an example of NEI-supported research that saves vision, in February 2013 the Food and Drug Administration (FDA) approved an implanted retinal prosthesis to treat adult patients with advanced retinitis pigmentosa (RP), a rare genetic condition that damages the retina and leads to blindness. A small video camera mounted on a pair of glasses sends images to a video processing unit that converts them to electronic data that is wirelessly transmitted to an array of electrodes implanted onto the retina. The device is enabling those who are otherwise completely blind to identify doors, crosswalks, and even utensils on a table. Although this "Bionic Eye" may have been a fantasy just a few short years ago, the NEI has always envisioned the future. Funding must be adequate for it to successfully pursue its goal of saving and restoring vision.

Blindness and Vision Loss is a Growing Public Health Problem That Individuals Fear and Would Trade Years of Life To Avoid

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Although the NEI estimates that the current annual cost of vision impairment and eye disease to the U.S. is \$68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's proposed fiscal year 2014 funding of \$699 million reflects just a little more than 1 percent of this annual cost of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to both the public and private sectors.

Vision loss also presents a real fear to most citizens:

- In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. NEI's Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a 1 to 10 scale, meaning greatest impact on their life.
- In patients with diabetes, going blind or experiencing vision loss rank among the top four concerns about the disease. These patients are so concerned about vision loss diminishing their quality of life that those with nearly perfect vision (20/20 to 20/25) would be willing to trade 15 percent of their remaining life for "perfect vision," while those with moderate impairment (20/30 to 20/100) would be willing to trade 22 percent of their remaining life for perfect vision. Patients who are legally blind from diabetes (20/200 to 20/400) would be willing to trade 36 percent of their remaining life to regain perfect vision.

The Academy Urges Congress To Fund NIH At \$32 Billion, NEI at \$730 Million, in Fiscal Year 2014 To Ensure the Momentum of Research, To Retain Trained Personnel, and Maintain U.S. Leadership

About the American Academy of Ophthalmology

The American Academy of Ophthalmology is the largest national membership association of Eye M.D.s. Eye M.D.s are ophthalmologists, medical and osteopathic

doctors who provide comprehensive eye care, including medical, surgical and optical care. More than 90 percent of practicing U.S. Eye M.D.s are Academy members, and the Academy has more than 7,000 international members.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the 90,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on fiscal year 2014 appropriations for Physician Assistant (PA) educational programs that are authorized through Title VII of the Public Health Service Act. AAPA respectfully requests the Senate Appropriations Committee to approve funding at existing levels for the Title VII health professions education program—\$264,400,000, with an allocation of 15 percent of the Primary Care Training and Enhancement program line for physician assistant training.

Title VII Health Professions Programs are essential to placing health professionals in medically underserved communities. A study published in the New York Times has shown we are currently short 9,000 primary care physicians, and that number will grow to 65,000 primary care physicians in 15 years. According to the Health Resources and Services Administration (HRSA), an additional 31,000 health care practitioners are needed to alleviate existing professional shortages. Title VII funding encourages greater numbers of students to enter PA educational programs and to go into primary care, while increasing access to care for millions of Americans who live in medically underserved areas.

Federal support for Title VII is authorized through section 747 of the Public Health Service Act. It is the only continuing Federal funding available to PA educational programs.

In 2012, 12 PA programs received \$2.3 million (5.9 percent of the total primary care medicine budget of \$38.9 million) in Title VII funding, which was directed to primary care education and training programs designed to prepare PAs for practice in urban or rural medically underserved areas. Additionally, these funds were directed to supporting programs that assist Veterans in their transition into becoming PAs in the civilian workforce. While the purview of the Title VII programs grant funding has expanded to include assisting returning combat veterans, the funds to PA programs from 2011 to 2012 has decreased by \$879,000. More reductions to this budget will hurt new PA programs that need these funds to help with student recruitment, faculty development, and establishing clinical rotation sites.

Diverse clinical rotation sites and recruitment programs are critical to PA education and are paramount to the Title VII primary care medicine program. A review of PA graduates from 1990–2009 demonstrates that PAs who have graduated from PA educational programs supported by Title VII are 67 percent more likely to be from underrepresented minority populations and 47 percent more likely to work in a rural health clinic than graduates of programs that were not supported by Title VII.

Title VII programs are essential to the development and training of primary health care professionals and, in turn, provide increased access to care by promoting health care delivery in medically underserved communities. We wish to thank the members of this subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support to augment funding to these important programs in fiscal year 2014.

Overview of Physician Assistant Education

The existing 170 accredited physician assistant educational programs are all located within schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 26 months of instruction, and the typical student has a bachelor's degree and about 4 years of prior health care experience. The PA curriculum includes 340 hours of basic sciences and nearly 1,600 hours of clinical medicine. On average, students devote more than 2,000 hours, or 50 to 55 weeks, to clinical education, divided between primary care medicine—family medicine, internal medicine, pediatrics, and obstetrics and gynecology—and various specialties, including surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry.

After graduation from an accredited PA program, physician assistants must pass a national certifying examination developed by the National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 con-

tinuing medical education hours every 2 years, and they must take a recertification exam every 6 years.

Physician Assistant Practice

Physician assistants (PAs) are licensed health professionals who practice medicine as members of a team with their supervising physicians. PAs exercise autonomy in medical decisionmaking and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 States, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience. Additionally, PAs are delegated prescriptive privileges by their physician supervisors in all 50 States, the District of Columbia, and Guam. This allows PAs to practice in rural, medically underserved areas where they are often the only full-time medical provider.

PAs in Primary Care

An estimated 30,000 PAs (30 percent of the profession) work in primary care across the nation—37 percent work in private practice (both physician group and solo practices); 3.1 percent practice in community health centers, 2.7 percent practice in certified rural health clinics, and 2.1 percent work in a federally qualified health center.

PAs are also one of three primary care providers who work in the National Health Service Corps (NHSC). The NHSC is an important Federal program with nearly 10,000 healthcare providers, like PAs, who benefit from the program's loan-forgiveness and scholarships awards to those providers and students who commit 2 years to provide medical, dental and mental healthcare in medically underserved areas.

Additionally, an estimated 2,790 PAs proudly work in community health centers (CHCs) around the country, some as CHC medical directors. Community health centers provide cost-effective healthcare throughout the country and serve as medical homes for millions in medically underserved areas. CHCs offer a wide variety of healthcare services through team-based care, providing high quality healthcare to CHC patients and significantly reducing medical expenses.

Critical Role of Title VII Public Health Service Act Programs

In its February 2012 report to Congress, HRSA's Advisory Committee on Training in Primary Care Medicine and Dentistry wrote: "The Title VII, section 747 grant programs have brought improvements in primary care education, faculty development, and workforce capacity. They have helped to identify and disseminate best practices to programs, accrediting bodies, and other stakeholders. These grants have permitted the development of innovative programs that benefit medical trainees throughout the country. Additionally, Title VII, section 747 grants are the foundation for programs that foster among academic leaders and trainees a sense of duty to provide care for underserved communities and populations."

Title VII programs are the only Federal educational programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurse training, and some allied health professions training have been paid through Graduate Medical Education (GME) funding; however, GME has never been available to support PA education. More importantly, GME was not intended to generate a supply of providers who are willing to work in the Nation's medically underserved communities—the purpose of Title VII.

Furthermore, Title VII programs seek to recruit students who are from underserved minority and disadvantaged populations, which is a critical step towards reducing persistent health disparities among certain racial and ethnic U.S. populations. Research shows racial and ethnic health disparities cost the economy more than \$230 billion in lost productivity and up to \$1.24 trillion in indirect costs over 3 years; and studies have found that health professionals from disadvantaged regions of the country are three to five times more likely to return to underserved areas to provide care which would help alleviate the current health disparity crisis in America.

Support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Title VII funding is a critical link in addressing the natural geographic mal-distribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation. Currently, 36 percent of PAs met their first clinical employer through their clinical rotations.

Supplementary Recommendations on fiscal year 2014 Funding

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all public health agencies and

programs when determining funding for fiscal year 2014. For instance, while it is critical, now more than ever, to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control and Prevention (CDC) that ensures a prompt response to an infectious disease outbreak or bioterrorist attack, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded.

HRSA administers the “people” programs, such as Title VII, that bring the results of cutting edge research at NIH to patients through providers such as PAs who have been educated in Title VII-funded programs. Likewise, the CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

Thank you for the opportunity to present the American Academy of Physician Assistants’ views on fiscal year 2014 appropriations concerning HRSA’s Title VII Health Professions Program.

PREPARED STATEMENT OF THE AMERICAN ALLIANCE OF MUSEUMS

Chairman Harkin, Ranking Member Moran, and members of the subcommittee, thank you for allowing me to submit this testimony. My name is Ford Bell and I serve as President of the American Alliance of Museums. I also submit this testimony on behalf of the larger museum community—including the American Association for State and Local History, the Association of Art Museum Directors, the Association of Science-Technology Centers, the Association of Science Museum Directors, the Association of Zoos and Aquariums, the Association of Children’s Museums, the American Public Gardens Association, and Heritage Preservation—to request that the subcommittee make a renewed investment in museums in fiscal year 2014. We urge you to fully fund the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) at its authorized level of \$38.6 million.

The Alliance is proud to represent the full range of our Nation’s museums—including aquariums, art museums, botanic gardens, children’s museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, planetariums, presidential libraries, science and technology centers, and zoos, among others—along with the professional staff and volunteers who work for and with museums. We are honored to work on behalf of the country’s 17,500 museums that employ 400,000 people and that annually spend more than \$2 billion on educational programming, deliver 18 million instructional hours to students and teachers, and directly contribute \$21 billion to their local economies.

IMLS is the primary Federal agency that supports the Nation’s museums, and OMS awards grants to help museums digitize, enhance and preserve their collections, provide teacher training, and create innovative, cross-cultural and multi-disciplinary programs and exhibits for schools and the public. The 2012–2016 IMLS Strategic Plan lists clear priorities: placing the learner at the center of the museum experience, promoting museums as strong community anchors, supporting museum stewardship of their collections, advising the President and Congress on how to sustain and increase public access to information and ideas, and serving as a model independent Federal agency maximizing value for the American public. IMLS is indeed a model Federal agency.

In late 2010, a bill to reauthorize IMLS for 5 years was enacted (by voice vote in the House and unanimous consent in the Senate). The bipartisan reauthorization included several provisions proposed by the museum field, including enhanced support for conservation and preservation, emergency preparedness and response, and statewide capacity building. The reauthorization also specifically supports efforts at the State level to leverage museum resources, including statewide needs assessments and the development of State plans to improve and maximize museum services throughout the State. The bill (now Public Law 111–340) authorized \$38.6 million for the IMLS Office of Museum Services to meet the growing demand for museum programs and services.

The final, post-sequestration, fiscal year 2013 funding level for OMS of \$29,245,034 represents a nearly 17 percent cut from the fiscal year 2010 appropriation of \$35,212,000. However, President Obama’s fiscal year 2014 budget proposes to partially restore these cuts by requesting \$32,923,270 for the Office of Museum Services. We strongly applaud the increased request, especially under current budgetary constraints.

To be clear, museums are essential in our communities for many reasons:

—*Museums are key education providers.*—They design exhibitions, educational programs, classroom kits, and online resources in coordination with State, local

and common core curriculum standards in math, science, art, literacy, language arts, history, civics and government, economics and financial literacy, geography, and social studies. Museums also offer experiential learning opportunities, STEM education, youth training, and job preparedness. They reach beyond the scope of instructional programming for schoolchildren by also providing critical teacher training. There is a growing consensus that whatever the new educational era looks like, it will focus on the development of a core set of skills: critical thinking, the ability to synthesize information, the ability to innovate, creativity, and collaboration. Museums are uniquely situated to help learners develop these core skills.

—*Museums create jobs and support local economies.*—Museums serve as economic engines, bolster local infrastructure, and spur tourism. Both the U.S. Conference of Mayors and the National Governors Association have noted that cultural assets such as museums are essential to attracting businesses, a skilled workforce, and local and international tourism.

—*Museums address community challenges.*—Many museums offer programs tailored to seniors, veterans, children with special needs, persons with disabilities, and more, greatly expanding their reach and impact. For example, some have programs designed specifically for children on the autism spectrum, some are teaching English as a Second Language, and some are working directly with Alzheimer's patients. Many museums facilitate job training programs, provide vegetable gardens for low-income communities, or serve as locations for supervised visits through the family court system. In 2012, more than 1,800 museums participated in the Blue Star Museums initiative, offering free admission to all active duty and reserve military personnel and their families from Memorial Day through Labor Day.

—*Digitization and traveling exhibitions bring museum collections to underserved populations.*—Teachers, students, and researchers benefit when cultural institutions are able to increase access to trustworthy information through online collections and traveling exhibits. Most museums, however, need more help in digitizing collections.

Grants to museums are highly competitive and decided through a rigorous, peer-reviewed process. Even the most ardent deficit hawks view the IMLS grant-making process as a model for the Nation. It would take approximately \$129 million to fund all the grant applications that IMLS received from museums in 2012. But given the significant budget cuts, many highly-rated grant applications go unfunded each year:

—Only 31 percent of Museums for America/Conservation Project Support projects were funded;

—Only 19 percent of National Leadership/21st Century Museum Professionals/Sparks Ignition Grants for Museums/Connecting to Collections Implementation projects were funded;

—Only 61 percent of Native American/Hawaiian Museum Services projects were funded; and

—Only 33 percent of African American History and Culture projects were funded.

It should be noted that each time a museum grant is awarded, additional local and private funds are also leveraged. In addition to the required dollar-for-dollar match required of museums, grants often spur additional giving by private foundations and individual donors. A recent IMLS study found that 67 percent of museums that received Museums for America grants reported that their IMLS grant had positioned the museum to receive additional private funding.

Here are just a few examples of how Office of Museum Services funding is used:

—The Alliance-accredited National Czech and Slovak Museum and Library in Cedar Rapids, Iowa will use its \$148,351 Museums for America grant awarded in 2011 to capture the personal stories and family sagas of Czech and Slovak Cold War émigrés recent (post-Velvet Revolution) Czech and Slovak immigrants to America. The project involves incorporating informational content and video clips into a new permanent exhibition. Other aspects of the project include design of a traveling exhibit, a conference, and the publication of an issue of the museum's journal, *Slovo*, which uses oral history content. This week, the museum will also receive IMLS' National Medal for Museum and Library Service, the country's highest honor for museums and libraries, for its essential role in rebuilding a Cedar Rapids neighborhood following devastating floods in 2008.

—The Alliance-accredited Edwin A. Ulrich Museum of Art at Wichita State University in Wichita, Kansas will use its \$150,000 Conservation Project Support grant awarded in 2012 to continue restoration work on Personages Oiseaux, the 26 x 52 foot glass-and-marble mosaic façade created and installed by Joan

Miró. The work is touted as “an icon for the museum, the university, the City of Wichita, and the State of Kansas.”

—The Prince George’s African American Museum & Cultural Center in North Brentwood, Maryland will use its \$147,308 African American History and Culture grant to support a museum curriculum and certification program. This grant, awarded in 2012, will increase professional knowledge and skills for community college students. The museum will work in partnership with the Workforce Development Program at Prince George’s Community College to create a curriculum model to share with other community colleges. The certification program is a training course revolving around a museum studies internship project highlighting African American history. The project will offer practical entry-level training experience to PGCC students interested in pursuing careers in museums.

—The Birmingham Zoo in Birmingham, Alabama will use its \$133,000 Museums for America grant, awarded in 2012, to support its Africa Zoo School program, which will aim to serve 1,200 students over 2 years. In partnership with Birmingham City Schools, the project will target all seventh-grade students within the city. Participating students, most attending low-performing schools, will attend a week-long “Zoo School” session, where they will be introduced to the Trails of Africa exhibit and will work through a related curriculum. The exhibit is the basis of an interdisciplinary experience to teach about the crisis of the elephant species’ survival in Africa, the cultures of people in Africa, and the scientific and engineering research involved in sustaining these populations. Students will develop critical thinking and problem-solving skills, which they can adapt to the classroom and home.

In closing, I would like to share with you for the record a recent letter to the subcommittee requesting funding for OMS signed by 24 of your Senate colleagues, including subcommittee members Senator Durbin, Senator Reed, and Senator Shaheen. Thank you once again for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Introduction

Mr. Chairman and members of the subcommittee, I am Peter Polverini, Dean of the University of Michigan School of Dentistry and President of the American Association for Dental Research (AADR). My testimony is on behalf of AADR. I thank the subcommittee for this opportunity to testify about the exciting advances in oral health science and for your past support of research at the National Institutes of Health (NIH). It is that support that makes it possible for the National Institute of Dental and Craniofacial Research (NIDCR) to improve oral health with the research it funds. The investments we make today will make it easier to treat and prevent oral health diseases and disorders in the future. Therefore, I am requesting that NIDCR receive a funding level of \$450 million. My testimony will illustrate how scientific advances in oral health have benefited taxpayers, and explain some of the challenges that lie ahead.

What is the American Association for Dental Research?

The AADR is a non-profit organization with more than 3,500 individual members in the United States, as well as 46 institutional members spread across 26 States. Its mission is to: 1) advance research and increase knowledge for the improvement of oral health; 2) support and represent the oral health research community; and 3) facilitate the utilization and knowledge of research findings.

Why is Oral Health Important?

Maintaining good oral health throughout life is critically important to systemic health and overall quality of life. If oral diseases and poor oral conditions go untreated, it becomes difficult to eat, drink, swallow, smile, talk, and maintain proper nutrition. In spite of the dramatic improvements in oral health over the years, it is still a major concern. Americans spent \$108 Billion on dental expenditures in 2011, according to the Center for Medicare and Medicaid Services (CMS). While tooth decay and gum disease remain the most prevalent, complete tooth loss, oral cancer, and craniofacial congenital anomalies, like cleft lip and palate are also health and economic burdens to the American people. Tooth decay, or dental caries, is a very common disease where the minerals in the tooth structure are slowly dissolved out of the tooth to the point of cavitation—or a “cavity.” Untreated dental decay in primary teeth affects 20 percent of children aged 2 to 5, and 25 percent of children 6 to 11. Untreated dental decay in permanent teeth also affects 20 to

25 percent of adults, depending on the age bracket. Moreover, we know there are significant oral health disparities across racial, ethnic, and socioeconomic groups.

Scientists have discovered important linkages between gum disease, or periodontal disease, and heart disease, stroke, diabetes, and pancreatic cancer. The consequences of inflammation may be the common biologic factor explaining these linkages, but there are genetic factors as well. Further research is needed to understand these linkages, the potential for causal connections, and the effect of intervention or treatment of the oral diseases on systemic health.

Examples of Oral Health Research and Development:

National Dental Practice-Based Research Network.—NIDCR recently awarded a seven-year grant that consolidates its dental practice-based research network initiative into a unified nationally coordinated effort. The consolidated initiative, renamed The National Dental Practice-Based Research Network (NDPBRN), is headquartered at the University of Alabama at Birmingham (UAB) School of Dentistry. A dental practice-based research network is an investigative union of practicing dentists and academic scientists. The network provides practitioners with an opportunity to propose or participate in research studies that address daily issues in oral health care. These studies help to expand the profession's evidence base and further refine care. According to NIDCR Director Martha Somerman, D.D.S., Ph.D., a national coordinating center streamlines the network structure for greater financial and administrative efficiency.

Human papillomavirus (HPV).—HPV is frequently associated with cervical cancer. However, HPV is responsible for a rapidly growing type of oral cancer. According to Maura L. Gillison, MD, PhD, an oncologist and researcher at Ohio State University, rates of infection among men are about three times higher than among women. Oral cancers are likely to become the most common HPV-related cancer by 2020. The International Agency for Research against Cancer has acknowledged HPV as a risk factor for oropharyngeal cancer. Since not enough is known about HPV-related oropharyngeal cancers to enable potentially lifesaving interventions, NIDCR plans to support research intended to provide a clearer picture of HPV-related oral cancers including their incidence, risk factors, and natural history.

Point of Care Diagnostics.—NIDCR is supporting studies aimed at providing early, point of care, detection of both oral and systemic conditions (e.g. oral cancer, pancreatic cancer, diabetes, cardiovascular disease). Point of care diagnostics are often more desirable than standard laboratory methods. Disease specific biomarkers found in saliva have recently provided important insights on human health. Saliva provides for noninvasive testing, potentially increasing the number of adverse health conditions detected at an early stage. Access to early diagnostic tests can save thousands of lives a year and can be conducted from home or mobile facilities reaching populations with limited access to health care. In order for the promise of salivary diagnostics to become a reality, there needs to be further research on the specific biomarkers that are thought to be associated with health or certain disease states.

Cleft Lip and/or Cleft Palate.—Craniofacial anomalies such as cleft lip and/or cleft palate (CLP) are among the most common birth defects. Both genetic and environmental factors contribute to oral clefts. Cleft lip is an abnormality in which the lip does not completely form during fetal development and cleft palate occurs when the roof of the mouth does not fully close, leaving an opening that can extend into the nasal cavity. Genome-wide association studies (GWAS) of cleft lip and/or cleft palate supported by NIDCR are providing important new leads about the role genetic factors and gene-environment interactions play in the development of these conditions. In addition, a DNA sequencing study is underway to identify less common genetic variants that influence the risk of developing cleft lip and/or cleft palate.

Health Disparities Research Program.—Despite remarkable improvements in the oral health of the American population, not everyone in the Nation has benefited equally. Oral, dental and craniofacial conditions remain among the most common health problems for low-income, racial/ethnic minority, disadvantaged, disabled, and institutionalized individuals across the life span. Dental caries, periodontal disease, and oral and pharyngeal cancer are of particular concern. The NIDCR Health Disparities Research Program supports studies that provide a better understanding of the basis of health disparities and inequalities, develops and tests interventions targeted to underserved populations; and explores approaches to the dissemination and implementation of effective findings to assure rapid translation into practice, policy and action in communities.

Chronic Pain.—NIDCR is an active participant in trans-NIH work on chronic pain. The Interagency Pain Research Coordinating Committee (IPRCC) is a Federal

advisory committee created by the Department of Health and Human Services to enhance pain research efforts and promote collaboration across the Government, with the ultimate goals of advancing fundamental understanding of pain and improving pain-related treatment strategies.

Challenges to Research

Today's investments in basic research on the fundamental causes and mechanisms of disease will have a great impact on future advances in health care. Investments in NIDCR are needed to support research to define the genetic and environmental risk factors for CLP, as well as to improve care for children with these disorders. More work needs to be done in order to understand HPV-related cancers, especially oral cancers given their increasing prevalence. These are just a couple of the many research challenges confronting oral health scientists. We urge Congress to make science a national priority.

Fiscal Year 2014 Budget Request

As you can see, Mr. Chairman, there are many research opportunities that need to be pursued in order to improve patient care. In order for Americans to have access to better oral health care, funding for NIH overall, and particularly NIDCR, should be more consistent. The budget sequestration, which went into effect March 1st, will have a devastating impact on science. Not only does it affect grants and cooperative agreements, but continuation awards will be reduced or in some cases not issued, thereby impeding ongoing research. New grants and cooperative agreements will likely be re-scoped, delayed, or canceled. These actions have direct implications on the health and safety of Americans. Moreover, the across-the-board cuts harm the prospects for lasting deficit reduction by stifling a significant driver of economic growth. We ask that you craft a solution that recognizes NIH as a critical national priority by providing at least \$32 billion in funding in the fiscal year 2014 Appropriations bill, of which we recommend that NIDCR be appropriated \$450 million.

Thank you for this opportunity to testify. We at AADR look forward to having the opportunity to work with the Congress and the Department of Health and Human Services to help build a strong and successful research enterprise.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN), which serves as the Nation's leading voice for baccalaureate and graduate nursing education, submits this testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies regarding fiscal year 2014. AACN represents over 720 schools of nursing that educate over 400,000 students and employ more than 16,000 full-time faculty members. Collectively, these institutions produce approximately half of our Nation's registered nurses (RNs) and all nurse faculty and researchers.

AACN respectfully requests that nursing education, research, and practice are strongly supported in fiscal year 2014 through an investment of \$251 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), \$150 million for the National Institute of Nursing Research (NINR) within the National Institutes of Health (NIH), and \$20 million for the Nurse-Managed Health Clinics (NMHCs) (Title III of the Public Health Service Act). A significant investment in these programs is paramount to ensuring that the nursing workforce can meet the healthcare needs of our country.

Demand for Nursing in Today's Healthcare System

Current transformations within our healthcare system to both the patient and provider sectors are creating an overwhelming demand for nursing services. Data from the Bureau of Labor Statistics (BLS) Employment Projections for 2010–2020, reveals that by year 2020, an additional 1.2 million RNs will be needed to keep pace with the growing demand. More specifically, the report anticipates that the number of nursing jobs will grow from 2.74 million in 2010 to 3.45 million in 2020. This projection translates to 712,000 nurses, or an increase of 26 percent. In addition, BLS expects another 495,500 nurses will be needed to replace those soon to retire.

The aging of the nursing workforce and America's patients underscores this alarming projection. According to the report *The U.S. Nursing Workforce: Trends in Supply and Demand* released by HRSA earlier this year, of the 2.8 million RNs currently practicing in America, 34.9 percent are over age 50, and 8.5 percent are over age 60. As this large segment of the workforce begins to retire, the Nation will soon

face a significant deficit in the number of experienced nurses available to provide services. Concurrent with the aging of the nursing workforce is the aging of America's Baby Boomer population. It is estimated that over 80 million Baby Boomers reached age 65 in 2011. As this population transitions into the Nation's oldest generation, these citizens will continue to require more primary care services related to chronic illness treatment, medication management, and patient education. A significant investment must be made in the education of new nurses to provide the Nation with the nursing services it requires.

Nursing Workforce Development Programs Answer the Call for an Expanded RN Workforce

In light of this demand, it is imperative that steadfast support for programs that educate future generations of nurses continues in fiscal year 2014. Investments made in the Title VIII Nursing Workforce Development programs today directly impact the supply and distribution of nurses entering into the pipeline for years to come. Between fiscal year 2007 and fiscal year 2011 alone, Title VIII programs supported over 300,000 nurses and nursing students across the country. These recipients are supported in academic and healthcare institutions and contribute to the advancement of nursing education, nursing science, and evidence-based practice. Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and aid in the recruitment and retention of nurses in the workforce.

Data from AACN's 2012–2013 Title VIII Student Recipient Survey highlight the significant influence that Title VIII dollars have on allowing more individuals to pursue nursing careers and for providing opportunities to practice in areas experiencing the greatest need for primary care services. The survey, which garnered responses from over 1,100 students, reflects how Title VIII programs impact the professional nursing continuum from entry-level education through graduation, and into long-term career planning. For example, 65 percent of respondents report that Title VIII funding affected their decision to enter nursing school, and 74 percent of respondents state that Title VIII funding allowed them to attend school full-time. These programs alleviate the financial burden that often prevents many students from graduating into the workforce sooner.

After graduation, respondents report that practicing in a community hospital or in an underserved community is ranked among their top career choices. Because Title VIII assistance relieves some of the pressure of finding a job based on salary, many students state they can pursue practice in an area they are truly passionate about: working with vulnerable populations to provide primary care, health promotion, and disease prevention. Moreover, personal testimony of several survey respondents reveals that many Title VIII recipients intend to practice in the community in which they were educated—a direct State investment.

However, a significant barrier preventing a greater number of nurses from entering into the workforce is a lack of nursing faculty. Data from AACN's 2012–2013 survey on enrollment and graduations shows that nursing schools were forced to turn away 79,659 qualified applications from entry-level baccalaureate and graduate nursing programs in 2012 due primarily to faculty vacancies. In fact, AACN's Special Survey on Faculty Vacancy for Academic Year 2012–2013 reveals that baccalaureate and graduate nursing programs report an average faculty vacancy rate of 7.6 percent for full-time positions and 6.8 percent for part-time positions. These vacancies limit the number of students admitted into nursing schools, and prevent more students from pursuing higher nursing education mandatory for career goals such as becoming an advanced practice registered nurse (APRN) or serving as nursing faculty. To counter this disparity, the Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education, provided they serve as faculty for 4 years after graduation.

AACN respectfully requests \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014.

National Institute of Nursing Research Improves the Quality and Quantity of Life

As one of the 27 Institutes and Centers at the NIH, the NINR is dedicated to providing the health professions workforce with evidence-based knowledge—an essential component to delivering high-quality, cost-effective care. NINR initiatives target chronic illnesses and communicable diseases that erode patient quality of life and the financial stability of patients, their families, and the healthcare system at large. For example, nurse scientists investigate how patient-centered practices can empower individuals to improve management of costly symptoms related to chronic ill-

ness. Moreover, while other healthcare research focuses heavily on the curative aspect of health care, NINR's research is largely aimed at expanding health promotion and disease prevention. This endeavor is central to the mission of averting any further increases in the rates of cardiac disease, obesity, diabetes, cancer, and other devastating illnesses plaguing our Nation's population.

One such study capturing this focus on prevention looked to reduce rates of high blood pressure among inner-city African-American males. This NINR-funded initiative supported a multidisciplinary healthcare team who educated this cohort and provided annual check-ups over the course of 3 years. The study resulted in the men practicing more healthy habits such as quitting smoking and moderating sodium intake. Furthermore, 44 percent of the men successfully lowered their blood pressure to within the normal range.

NINR also funds research that advances innovation in healthcare practices. NINR has committed to undertaking a comprehensive examination of how genetics and genomics affect treatment options for certain patient populations, and offers intensive programs to educate participants on the role of molecular genetics in nursing practice.

Additionally, NINR allocates a generous 6 percent of its overall budget to the education and training of nurse researchers, many of whom dually serve as nurse faculty within our Nation's nursing schools. This is crucial given the need for more doctorally prepared nurse faculty.

AACN respectfully requests \$150 million for the NINR in fiscal year 2014.

Nurse-Managed Health Clinics Provide Primary Care and Clinical Training Space

More than ever, the healthcare workforce is questioning how it will successfully provide primary care services to millions of Americans in need. NMHCs offer one such solution. Managed by APRNs and often staffed by an interdisciplinary health provider team, NMHCs provide necessary primary care services to medically underserved communities. These centers treat patients regardless of their ability to pay, and serve as critical access points to keep patients out of the emergency room, saving the healthcare system millions of dollars annually. Moreover, NMHCs allow practitioners to foster a community environment conducive for patient teaching which is a critical facet of health promotion.

Often associated with a school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency, NMHCs also serve as clinical education training sites for students of nursing, medicine, physical therapy, social work, and ancillary healthcare services. This function is an essential aspect of these clinics as nursing schools report a lack of clinical training sites a primary barrier to accepting more new students into their programs.

AACN respectfully requests \$20 million for the Nurse-Managed Health Clinics in fiscal year 2014.

AACN acknowledges the challenge set before the subcommittee of ensuring adequate healthcare services to the public while striving for financial sustainability. AACN respectfully urges the subcommittee's thoughtful consideration of our requests for the aforementioned programs that are vital to a robust nursing workforce and a healthy Nation. We ask that you do so by providing \$251 million for the Title VIII Nursing Workforce Development programs, \$150 million for the National Institute of Nursing Research, and \$20 million for Nurse-Managed Health Clinics in fiscal year 2014.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF
OSTEOPATHIC MEDICINE

On behalf of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to submit this testimony in support of vital funding for programs at the Health Resources Services Administration (HRSA), the National Institutes of Health (NIH), and the Agency for Healthcare Research and Quality (AHRQ) in fiscal year 2014. AACOM represents the administrations, faculty, and students of the Nation's 29 colleges of osteopathic medicine at 37 locations in 28 States. Today, more than 21,000 students are enrolled in osteopathic medical schools. Nearly one in five U.S. medical students is training to be an osteopathic physician. AACOM strongly supports funding of \$520 million for HRSA's Title VII and VIII programs under the Public Health Service Act; funding the HRSA Teaching Health Center Graduate Medical Education (THCGME) Development Grants at \$10 million minimally; sustainment of student scholarship and loan repayment programs for graduate and professional students at the U.S. Department of Education and opposition of any rescissions from the National Health Service Corps (NHSC) Fund cre-

ated under the Affordable Care Act (ACA, Public Law 111–142 and Public Law 111–152); appropriating \$3 million to fund the National Health Care Workforce Commission; sufficient funding for the NIH; and appropriating \$430 million for the AHRQ.

Title VII

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through HRSA, support the training and education of health practitioners to enhance the supply, diversity, and distribution of the health care workforce, acting as an essential part of the health care safety net and filling the gaps in the supply of health professionals not met by traditional market forces. Title VII and Title VIII nurse education programs are the only Federal programs designed to train clinicians in interdisciplinary settings to meet the needs of special and underserved populations, as well as increase minority representation in the health care workforce.

According to HRSA, an additional 33,000 health care practitioners are needed to alleviate existing health professional shortages. Combined with faculty shortages across health professions disciplines, racial and ethnic disparities in health care, a growing, aging population, and the anticipated demand for increased access to care, these needs strain an already fragile health care system. AACOM appreciates the investments that have been made in these programs, and we urge the subcommittee to fund \$520 million for the Title VII and VIII programs to include support for the following programs in order to include: the Primary Care Training and Enhancement (PCTE) Program, the Health Careers Opportunity Program (HCOP), the Centers of Excellence (COE), the Geriatric Education Centers (GECs) and the Area Health Education Centers (AHECs). Strengthening the workforce has been recognized as a national priority, and the investment in these programs recommended by AACOM will help meet the demand facing this country for a well-trained, diverse workforce.

Teaching Health Centers Graduate Medical Education Program

HRSA's THCGME Program is the first of its kind to shift GME training to community-based care settings that emphasize primary care and prevention. It is uniquely positioned to provide much-needed primary care training in underserved populations. However, because the program is the first of its kind, most community-based settings do not have existing infrastructures to provide this training. AACOM strongly supports funding the THCGME Development Grants at \$10 million minimally, which was the level of the fiscal year 2013 President's budget request. This funding would allow potential THCGME training sites to develop the infrastructure needed to administer residency training programs.

National Health Service Corps

Approximately 50 million Americans live in communities with a shortage of health professionals, lacking adequate access to primary care. Through scholarships and loan repayment, the NHSC supports the recruitment and retention of primary care clinicians to practice in underserved communities. The self-reported average medical educational debt of graduates of colleges of osteopathic medicine (COMs) who borrowed to attend medical school increased from less than \$121,000 in 2000 to \$205,674 for 2012 graduates, with 91 percent of 2012 graduates reporting that they had medical education debt. Today, nearly 10,000 National Health Service Corps providers are providing primary care to approximately 10.4 million people at nearly 14,000 health care sites in urban, rural, and frontier areas. AACOM strongly supports the preservation of student scholarship and loan repayment programs for graduate and professional students. This critical funding works to address the primary care workforce shortage and advances innovative models of service, such as HRSA's Students to Service pilot program which provides loan repayment assistance to medical students in their last year of education in return for their commitment to practice.

Workforce Commission

As the United States struggles to address health care provider shortages in certain specialties and in rural and underserved areas, the country lacks a defined policy to address these critical issues. The National Health Care Workforce Commission was designed to develop and evaluate training activities to meet demand for health care workers. Without funding, the Commission cannot identify barriers that may create and exacerbate workforce shortages and improve coordination on the Federal, State, and local levels. Having this type of coordinating body in place is becoming more critical as more Americans have insurance coverage and as the population ages, requiring access to care. For these reasons, AACOM recommends that \$3 million be appropriated to fund the Commission.

National Institutes of Health

Research funded by the National Institutes of Health (NIH) leads to important medical discoveries regarding the causes, treatments, and cures for common and rare diseases, as well as disease prevention. These efforts improve our Nation's health and save lives. To maintain a robust research agenda, further investment will be needed. AACOM recommends a sufficient level of funding for the NIH.

In today's increasingly demanding and evolving medical curriculum, there is a critical need for more research geared toward evidence-based osteopathic medicine. AACOM believes that it is vitally important to maintain and increase funding for biomedical and clinical research in a variety of areas related to osteopathic principles and practice, including osteopathic manipulative medicine and comparative effectiveness. In this regard, AACOM encourages support for the NIH's National Center for Complementary and Alternative Medicine (NCCAM) to continue fulfilling this essential research role.

Agency for Healthcare Research and Quality

AHRQ supports research to improve health care quality, reduce costs, advance patient safety, decrease medical errors, and broaden access to essential services. AHRQ plays an important role in producing the evidence base needed to improve our Nation's health and health care. The incremental increases for AHRQ's Patient Centered Health Research Program in recent years, as well as the funding provided to AHRQ in the American Recovery and Reinvestment Act of 2009 (ARRA), will help AHRQ generate more of this research and expand the infrastructure needed to increase capacity to produce this evidence. More investment is needed, however, to fulfill AHRQ's mission and broader research agenda, especially research in patient safety and prevention and care management research. AACOM recommends \$430 million for AHRQ's base, discretionary budget. This investment will preserve AHRQ's current programs while helping to restore its critical health care safety, quality, and efficiency initiatives. AACOM is grateful for the opportunity to submit its views and looks forward to continuing to work with the subcommittee on these important matters.

PREPARED STATEMENT OF THE THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), the world's largest professional association of research scientists and physicians who are experts on the immune system, respectfully submits this testimony regarding appropriations for the National Institutes of Health (NIH) for fiscal year 2014. AAI recommends an appropriation of at least \$32 billion for NIH for fiscal year 2014 to enable NIH to support existing research projects, fund a limited number of outstanding new ones, and ensure that the brightest students and trainees are able to pursue careers in biomedical research in the United States.

The Irreplaceable Role of NIH in Advancing Biomedical Research

NIH grants support the work of most biomedical scientists.¹ The vast majority of AAI members who work in academia depend on NIH grants to support their research at universities, colleges and research institutions all around the country; many also teach the medical, graduate, and undergraduate students who will be the next generation of physicians and researchers. Many AAI members who work in Government are employed by the NIH; they depend on the NIH budget—as well as regular interaction with their private sector colleagues—to advance their work.² Our industry members, who generally do not receive NIH grants or awards, nonetheless depend on scientific discoveries that are generated by NIH-funded researchers to catalyze translational research or develop products. No matter where on the spectrum of biomedical science researchers may work, they know that NIH is the lynchpin to, and essential ingredient for, success.

¹After a highly competitive peer review, NIH distributes most (more than 80 percent) of its \$30.7 billion budget to scientists who conduct research at approximately 2,500 universities, medical schools, and other research institutions across the United States. About 11 percent of its budget supports the work of the approximately 6,000 scientists who work in NIH's own laboratories. <http://nih.gov/about>

²AAI is concerned that Federal policy limits the ability of Government scientists to attend privately sponsored scientific meetings and conferences. See <http://www.whitehouse.gov/sites/default/files/omb/memoranda/2012/m-12-12.pdf> http://www.hhs.gov/travel/policies/2012_policy_manual.pdf. Government scientists contribute significantly to scientific advancement in our field. Information exchange among scientists from Government, academia, industry and private research institutes is absolutely essential, and any barriers to the participation of Government scientists undermine the best interests of science.

NIH's irreplaceable role in our Nation's biomedical research enterprise is indisputable among scientists. And the partnership between Government-funded research and advancements in the private sector has never been more clear or more necessary: in a recent article in *Forbes*, three "current and former leaders of major commercial and academic life science institutions" (Marc Tessier-Lavigne, Ph.D., P. Roy Vagelos, M.D., and Elias Zerhouni, M.D.)³ compellingly argue that the "tiny" Federal investment in NIH research has reaped "enormous benefits—human and economic" and that "continued investment in basic science is . . . key to our economic competitiveness. America remains the world's leader in biotechnology and pharmaceutical discovery thanks to the strength of our research universities and other biomedical research institutions, which not only spawn countless biotechnology companies but also have attracted the R&D operations of most major pharmaceutical companies, which are keen to tap into our innovation." Those who suggest that the private sector can or will fill the gap left by inadequate NIH funding miss the essential point made by these internationally recognized scientific leaders: NIH-funded research and NIH leadership provide the foundation upon which commercial discovery and development depend.

Inadequate NIH Funding Threatens Human Health and U.S. Preeminence in Medicine

America's dominance in advancing basic biomedical research, discovering urgently needed treatments and cures, and "growing" brilliant young scientists has been unchallenged for more than fifty years. However, erosion of the NIH budget over the last decade has already led to the loss of grant funding among even the most highly qualified scientists, resulting in the closure of labs, the termination or interruption of important research, and the emigration of talented scientists to other countries that are investing heavily in their futures.⁴ For those scientists who are willing and able to continue, securing funding increasingly consumes their time—time that should be devoted to research and to mentoring the Nation's future researchers, inventors and innovators. And in a relatively new discipline such as immunology, where knowledge is expanding exponentially and the potential for even greater success is palpable, this shrinking of Federal resources is both alarming and a squandering of precious prior Federal investment.

The Immune System and Its Impact on Disease

The functional immune system recognizes and attacks bacteria, viruses, and tumor cells inside the body. Many infectious agents, including influenza, HIV/AIDS, tuberculosis, malaria, and the common cold, challenge—and sometimes overcome—the defenses mounted by the immune system, resulting in disease. A malfunctioning immune system can attack our normal body tissues, causing "autoimmune" diseases or disorders, including Type 1 diabetes, multiple sclerosis, rheumatoid arthritis, asthma, allergies, inflammatory bowel diseases, and lupus. The immune system also plays a role in many other diseases and conditions, including cancer, Alzheimer's disease, obesity, Type II diabetes, and cardiovascular disease. Understanding the immune response is also crucial to developing protective vaccines against pathogens that might cause the next pandemic, man-made and natural infectious organisms (including plague, smallpox and anthrax) that could be used for bioterrorism, and environmental threats that could cause or exacerbate disease. Immunologists have made great progress in many of these areas, but solving key scientific questions that lead to prevention and cures cannot occur without investigator-initiated peer-reviewed research supported by a strong, adequately funded NIH.⁵

³Dr. Lavigne is President of The Rockefeller University and former Chief Scientific Officer for Genentech Inc.; Dr. Vagelos is Chairman of Regeneron Pharmaceuticals and Retired Chairman and CEO of Merck & Co., Inc.; and Dr. Zerhouni is President of Research and Development for Sanofi and former Director of NIH. "Legendary Drug Industry Executives Warn U.S. Science Cuts Endanger The Future," *Forbes* online (3/6/13) <http://www.forbes.com/sites/matthewherper/2013/03/06/drug-industry-greats-say-the-u-s-must-reverse-the-cuts-to-our-investment-in-science/>

⁴See "U.S. cuts could lead to brain drain in medicine," *The Baltimore Sun*, 2/23/13, http://articles.baltimoresun.com/2013-02-23/news/bs-md-research-funding-20130221_1_nih-grants-researchers-head-first-grant. See also Atkinson, *et al.* 2012, "Leadership in Decline," The Information Technology and Innovation Foundation <http://www2.itif.org/2012-leadership-in-decline.pdf>

⁵NIH should robustly fund and primarily rely on individual investigator-initiated research, in which researchers working in institutions across the Nation submit applications to, and following independent peer review, receive grants from, NIH. Biomedical innovation and discovery are less likely to be achieved through "top-down" science, in which the Government specifies the type of research it wishes to fund.

Recent Immunological Advances and Their Promise for Tomorrow

A potential cure for cancer?—NIH-funded scientists have demonstrated that they can remove a specific subset of immune cells (T lymphocytes) from individuals with cancer, genetically modify them in the laboratory to recognize the patient's own cancer cells, and administer those cells to the patient. This personalized immunotherapy has induced complete and partial remissions in patients in a recent clinical experiment. Scientists have also shown similar techniques could induce cures in other types of cancer, including metastatic melanoma (a type of skin cancer), which is one of the ten most common cancers.⁶

A way to stop Alzheimer's disease?—Alzheimer's disease (AD) is a neurodegenerative disease of the brain that currently afflicts 5.4 million Americans, mostly over age 65.⁷ While the cause of AD is unknown, researchers have recently found evidence of immune cells present in AD lesions, systemic alteration in the immune system of AD patients, and local inflammation in the brains of those with AD. Such recent discoveries are leading scientists to develop immune based therapies to treat AD patients, including monoclonal antibodies which target AD plaques for destruction, and DNA based vaccines. Such potential treatments are under development in many NIH-funded laboratories.

New treatments for emerging zoonotic infectious diseases?—Zoonotic infections (human infections acquired from a different animal species) include avian influenza, SARS, hantavirus, dengue virus, Nipah virus, and West Nile virus. Although the overall incidence remains low, these infections can have high mortality rates and emerge without warning, as evidenced by the 2012 hantavirus outbreak in Yosemite National Park and the severe West Nile virus season.⁸ Developing preventive vaccines for these infections has proven difficult, and current treatments are limited. NIH-funded research on hantavirus and influenza A has shown an association between illness/death and an inappropriately strong immune response caused by an excessive release of cytokines (hormones of the immune system). Researchers are exploring whether limiting the inappropriate immune response during infection can reduce virus-induced illness and death.⁹

The Importance of Sustained NIH Funding to Research, Scientists and Our Nation

Despite strong Congressional support for biomedical research and NIH, fiscal pressures in recent years have resulted in flat or reduced NIH funding. After accounting for increases in biomedical research inflation, these budgets have eroded NIH's purchasing power by about 20 percent since 2003. Under sequestration, with its fiscal year 2013 budget cut of about 5.1 percent, NIH's purchasing power will be further reduced. AAI is deeply alarmed about this funding reduction and believes it could irreparably harm ongoing research, weaken the U.S. biomedical research enterprise, and enable global competitors to recruit away our best scientists.

Looking Ahead: The President's fiscal year 2014 Budget

AAI greatly appreciates that the President's budget for fiscal year 2014 reflects his deep commitment to research and innovation by providing increased funding for NIH. Although the increase (\$471 million, or 1.6 percent) is small, it includes \$382 million to support an additional 351 research project grants, a welcome boost for researchers hit hard by an NIH budget eroded by inflation and sequestration.¹⁰ Although AAI believes, as stated above, that NIH needs a budget of at least \$32 billion for fiscal year 2014, we appreciate that the President recognizes the urgent im-

⁶See Kalos *et al.* 2011, "T Cells with Chimeric Antigen Receptors Have Potent Antitumor Effects and Can Establish Memory in Patients with Advanced Leukemia," *Science Translational Medicine*, 3:95 <http://stm.sciencemag.org/content/3/95/95ra73.short>; Porter *et al.* 2011, "Chimeric Antigen Receptor—Modified T Cells in Chronic Lymphoid Leukemia," *N England J Med* 365:725–733 <http://www.nejm.org/doi/full/10.1056/NEJMoa1103849>.

⁷See http://www.alz.org/documents_custom/2012_facts_figures_fact_sheet.pdf. The Alzheimer's Association estimates that up to 16 million people will have Alzheimer's by 2050. And the costs are staggering: "In 2012, the direct costs of caring for those with Alzheimer's . . . will total an estimated \$200 billion . . . Unless something is done, the costs of Alzheimer's in 2050 are estimated to total \$1.1 trillion (in today's dollars). Costs to Medicare and Medicaid will increase nearly 500 percent."

⁸See <http://www.cdc.gov/hantavirus/outbreaks/yosemite-national-park-2012.html> and <http://www.cdc.gov/ncidod/dvbid/westnile/index.htm>.

⁹See Tejaro *et al.* 2011, "Endothelial Cells Are Central Orchestrators of Cytokine Amplification during Influenza Virus Infection," *Cell* 146:980–991 <http://www.sciencedirect.com/science/article/pii/S009286741100941X>.

¹⁰Given the scarcity of funding currently available to support ongoing and new research, AAI is concerned about the budget's relatively large funding level for new initiatives and targeted disease research, as well as substantial funding increases to rapidly grow some newer programs, potentially at the expense of investigator-initiated basic research.

portance of investing in biomedical research to the health and economic well-being of the American people.

Conclusion

AAI thanks the members and staff of the subcommittee for their strong bipartisan support for biomedical research, and urges an appropriation of at least \$32 billion for NIH for fiscal year 2014 to fund important ongoing research, strengthen the biomedical research enterprise, and support the thousands of scientists across the Nation who devote their lives to finding the answers we need to prevent, treat, and cure disease.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

FISCAL YEAR 2014 APPROPRIATIONS REQUEST SUMMARY

	Fiscal Year 2013 Actual	Fiscal Year 2014 Budget	AANA Fiscal Year 2014 Request
HHS/HRSA/BHPr Title 8 Advanced Education Nursing, Nurse Anesthetist Education Reserve.	Awaiting grant allocations—in fiscal year 2012 awards amounted to approx. \$3.5MM.	Grant allocations not specified.	\$4 MM for nurse anesthesia education
Total for Advanced Education Nursing, from Title 8.	\$60.8 MM for Advanced Education Nursing postsequester estimate.	Not yet available for Advanced Education Nursing.	\$83.925 MM for advanced education nursing
Title 8 HRSA BHPr Nursing Education Programs.	\$220.4 MM postsequester estimate.	Not yet available	\$251.099 MM

About the American Association of Nurse Anesthetists (AANA) and Certified Registered Nurse Anesthetists (CRNAs)

The AANA is the professional association for more than 45,000 CRNAs and student nurse anesthetists, representing over 90 percent of the nurse anesthetists in the United States. Today, CRNAs deliver approximately 33 million anesthetics to patients each year in the U.S. CRNA services include administering the anesthetic, monitoring the patient's vital signs, staying with the patient throughout the surgery, and providing acute and chronic pain management services. CRNAs provide anesthesia for a wide variety of surgical cases and in some States are the sole anesthesia providers in almost 100 percent of rural hospitals, affording these medical facilities obstetrical, surgical, and trauma stabilization, and pain management capabilities. CRNAs work in every setting in which anesthesia is delivered, including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers (ASCs), pain management units and the offices of dentists, podiatrists and plastic surgeons.

Nurse anesthetists are experienced and highly trained anesthesia professionals whose record of patient safety is underscored by scientific research findings. The landmark Institute of Medicine report *To Err is Human* found in 2000 that anesthesia was 50 times safer then than in the 1980s. (Kohn L, Corrigan J, Donaldson M, ed. *To Err is Human*. Institute of Medicine, National Academy Press, Washington DC, 2000.) Though many studies have demonstrated the high quality of nurse anesthesia care, the results of a new study published in *Health Affairs* led researchers to recommend that costly and duplicative supervision requirements for CRNAs be eliminated. Examining Medicare records from 1999–2005, the study compared anesthesia outcomes in 14 States that opted-out of the Medicare physician supervision requirement for CRNAs with those that did not opt out. (To date, 17 States have opted-out.) The researchers found that anesthesia has continued to grow more safe in opt-out and non-opt-out States alike. (Dulisse B, Cromwell J. *No Harm Found When Nurse Anesthetists Work Without Supervision By Physicians*. *Health Aff.* 2010;29(8):1469–1475.)

CRNAs provide the lion's share of anesthesia care required by our U.S. Armed Forces through active duty and the reserves, staffing ships, remote U.S. military bases, and forward surgical teams without physician anesthesiologist support. In addition, CRNAs predominate in rural and medically underserved areas, and where more Medicare patients live (Government Accountability Office. Medicare and private payment differences for anesthesia services. GAO–07–463, Washington DC, Jul. 27, 2007. <http://www.gao.gov/products/GAO-07-463>).

Importance of and Request for HRSA Title 8 Nurse Anesthesia Education Funding

Our profession's chief request of the subcommittee is for \$4 million to be reserved for nurse anesthesia education and \$83.925 million for advanced education nursing from the HRSA Title 8 program, out of a total Title 8 budget of \$251.099 million. We request that the Report accompanying the fiscal year 2014 Labor-HHS-Education Appropriations bill include the following language: "Within the allocation, the Committee encourages HRSA to allocate funding at least at the fiscal year 2012 level for nurse anesthetist education." This funding request is justified by the safety and value proposition of nurse anesthesia, and by anticipated growth in demand for CRNA services as baby boomers retire, become Medicare eligible, and require more healthcare services. In making this request, we associate ourselves with the request made by The Nursing Community and Americans for Nursing Shortage Relief (ANSR) with respect to Title 8 and the National Institute of Nursing Research (NINR) at the National Institutes of Health.

The Title 8 program, on which we will focus our testimony, is strongly supported by members of this subcommittee in the past, and is an effective means to help address nurse anesthesia workforce demand. In expectation for dramatic growth in the number of U.S. retirees and their healthcare needs, funding the advanced education nursing program at \$83.925 million is necessary to meet the continuing demand for nursing faculty and other advanced education nursing services throughout the U.S.. The program funds competitive grants that help enhance advanced nursing education and practice, and traineeships for individuals in advanced nursing education programs. It also targets resources toward increasing the number of providers in rural and underserved America and preparing providers at the master's and doctoral levels, thus increasing the supply of clinicians eligible to serve as nursing faculty, a critical need.

Demand remains high for CRNA workforce in clinical and educational settings. A 2007 AANA nurse anesthesia workforce study found a 12.6 percent CRNA vacancy rate in hospitals and a 12.5 percent faculty vacancy rate. The supply of clinical providers has increased in recent years, stimulated by increases in the number of CRNAs trained. From 2002–2012, the annual number of nurse anesthesia educational program graduates increased from 1,362 to 2,469, according to the Council on Accreditation of Nurse Anesthesia Educational Programs (COA). The number of accredited nurse anesthesia educational programs grew from 85 to 113. We anticipate increased demand for anesthesia services as the population ages, the number of clinical sites requiring anesthesia services grows, and a portion of the CRNA workforce retires.

The capacity of our 113 nurse anesthesia educational programs to educate qualified applicants is limited by the number of faculty, the number and characteristics of clinical practice educational sites, and other factors—and they continue turning away hundreds of qualified applicants. A qualified applicant to a CRNA program is a bachelor's educated registered nurse who has spent at least 1 year serving in an acute care healthcare practice environment. They are prepared in nurse anesthesia educational programs located all across the country, including Arkansas, California, Connecticut, Georgia, Kentucky, Maryland, New York, Ohio, and Tennessee. To meet the nurse anesthesia workforce challenge, the capacity and number of CRNA schools must continue to grow and modernize with the latest advancements in simulation technology and distance learning consistent with improving educational quality and supplying demand for highly qualified providers. With the help of competitively awarded grants supported by Title 8 funding, the nurse anesthesia profession is making significant progress, but more is required.

This progress is extremely cost-effective from the standpoint of Federal funding. Anesthesia can be provided by nurse anesthetists, physician anesthesiologists, or by CRNAs and anesthesiologists working together. Of these, the nurse anesthesia practice model is by far the most cost-effective, and ensures patient safety. (Hogan P et al. Cost effectiveness analysis of anesthesia providers. *Nursing Economic*, Vol. 28 No. 3, May-June 2010, p. 159 et seq.) Nurse anesthesia education represents a significant educational cost-benefit for competitively awarded Federal funding in support of CRNA educational programs.

Support for Safe Injection Practices and the Alliance for Injection Safety

As a leader in patient safety, the AANA has been playing a vigorous role in the development and projects of the Alliance for Injection Safety, intended to reduce and eventually eliminate the incidence of healthcare facility acquired infections. In the interest of promoting safe injection practice, and reducing the incidence of healthcare facility acquired infections, we associate ourselves with the AIS recommendation.

PREPARED STATEMENT OF THE AMERICAN CONGRESS OF OBSTETRICIANS AND
GYNECOLOGISTS

The American Congress of Obstetricians and Gynecologists (ACOG), representing 57,000 physicians and partners in women's health care, is pleased to offer this statement to the Senate Committee on Appropriations, Subcommittee on Labor, Health and Human Services, and Education. We thank Chairman Harkin, and the entire subcommittee for the opportunity to provide comments on some of the most important programs to women's health.

Today, the U.S. lags behind other nations in healthy births, yet remains high in birth costs. ACOG's Making Obstetrics and Maternity Safer (MOMS) Initiative seeks to improve maternal and infant outcomes through investment in all aspects of the cycle of research, including comprehensive data collection and surveillance, biomedical research, and translation of research into evidence-based practice and programs delivered to women and babies. ACOG supports S. 425, the Quality Care for Moms and Babies Act, introduced by Sen. Debbie Stabenow, which would greatly improve maternity care delivery through quality collaboratives and quality measure development. This legislation depends on the investments made by Congress in research and programs that provide robust data to inform quality improvement initiatives. We urge you to make funding of the following programs and agencies a top priority in fiscal year 2014.

Data Collection and Surveillance at the Centers for Disease Control and Prevention (CDC)

In order to conduct robust research, uniform, accurate and comprehensive data and surveillance are critical. The National Center for Health Statistics is the Nation's principal health statistics agency and collects State data from records like birth certificates that give us raw, vital statistics. The birth certificate is the key to gathering vital information about both mother and baby during pregnancy and labor and delivery. The 2003 U.S.-standard birth certificate collects a wealth of knowledge in this area, yet not all States are using it. States without these resources are likely underreporting maternal and infant deaths and complications from childbirth and causes of these deaths remain unknown. Use must be expanded to all 50 States, ensuring that uniform, accurate data is collected nationwide. For fiscal year 2014, ACOG requests \$162 for the National Center for Health Statistics and \$18 million within that funding request to modernize the National Vitals Statistics System, which would help States update their birth and death records systems.

The Pregnancy Risk Assessment Monitoring System (PRAMS) at CDC extends beyond vital statistics and surveys new mothers on their experiences and attitudes during pregnancy, with questions on a range of topics, including what their insurance covered, whether they had stressful experiences during pregnancy, when they initiated prenatal care, and what kinds of questions their doctor covered during prenatal care visits. By identifying trends and patterns in maternal health, researchers better understand indicators of preterm birth and other health conditions. This data allows CDC and State health departments to identify behaviors and environmental and health conditions that may lead to preterm births. Only 40 States use the PRAMS surveillance system today. ACOG requests adequate funding to expand PRAMS to all U.S. States and territories.

Biomedical Research at the National Institutes of Health (NIH)

Biomedical research is critically important to understanding the causes of prematurity and developing effective prevention and treatment methods. Prematurity rates have increased almost 35 percent since 1981, and cost the Nation \$26 billion annually, \$51,600 for every infant born prematurely. Direct health care costs to employers for a premature baby average \$41,610, 15 times higher than the \$2,830 for a healthy, full-term delivery. Research into maternal morbidity, beginning with developing a consensus definition for severe maternal morbidity, is an important component of understanding pregnancy outcomes, including prematurity. The National Institute on Child Health and Human Development (NICHD) has included in its Vision Statement a goal of determining the complex causes of prematurity and developing evidence-based measures for its prevention within the next 10 years. Sustaining the investments at NIH is vital to achieving this goal, and therefore ACOG supports a minimum of \$32 billion for NIH and \$1.37 billion within that funding request for NICHD in fiscal year 2014.

Adequate levels of research require a robust research workforce. The average investigator is in his/her forties before receiving their first NIH grant, a huge disincentive for students considering bio-medical research as a career. Complicating matters, there is a gap between the number of women's reproductive health researchers being trained and the need for such research. Programs like the Women's Reproduc-

tive Health Research (WRHR) Career Development program, Reproductive Scientist Development Program (RSDP), and the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program all seek to address the shortfall of women's reproductive health researchers. At least 79 percent of BIRCWH grantees go on to apply for NIH grants, and 51 percent receive NIH grants, much higher than the average NIH success rate. Sequestration and other budget cuts threaten to undermine these programs at a critical juncture. For example, every \$500,000 cut to the BIRCWH program results in one less BIRCWH scholar. A sustained investment in NIH funding will help ensure the continuation of these programs and help mitigate the negative consequences of budget uncertainty on the future research workforce.

Public Health Programs at the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC)

Projects at HRSA and CDC are integral to translating research findings into evidence-based practice changes in communities. Where NIH conducts research to identify causes of preterm birth, CDC and HRSA fund programs that provide resources to mothers to help prevent preterm birth, and help identify factors contributing to preterm birth and poor maternal outcomes. The Maternal Child Health Block Grant at HRSA is the only Federal program that exclusively focuses on improving the health of mothers and children. State and territorial health agencies and their partners use MCH Block Grant funds to reduce infant mortality, deliver services to children and youth with special health care needs, support comprehensive prenatal and postnatal care, screen newborns for genetic and hereditary health conditions, deliver childhood immunizations, and prevent childhood injuries.

These early health care services help keep women and children healthy, eliminating the need for later costly care. For example, every \$1 spent on preconception care for women with diabetes can reduce health costs by up to \$5.19 by preventing costly complications in both mothers and babies. Every \$1 spent on smoking cessation counseling for pregnant women saves \$3 in neonatal intensive care costs. The MCH Block Grant has seen an almost \$30 million decrease in funding in the past 5 years alone. ACOG urges you not to cut the MCH Block Grant any further and for fiscal year 2014 we request \$640 million for the Block Grant to maintain its current level of services.

Family planning is essential to helping ensure healthy pregnancies and reducing the risk of preterm birth. The Title X Family Planning Program provides services to more than five million low-income men and women at more than 4,500 service delivery sites. Every \$1 spent on family planning results in a \$4 savings to Medicaid. Services provided at Title X clinics accounted for \$3.4 billion in health care savings in 2008 alone. ACOG supports \$327 million for Title X in fiscal year 2014 to sustain its level of services.

The Healthy Start Program through HRSA promotes community-based programs that help reduce infant mortality and racial disparities in perinatal outcomes. These programs are encouraged to use the Fetal and Infant Mortality Review (FIMR) which brings together ob-gyn experts and local health departments to help specifically address local issues contributing to infant mortality. Today, more than 220 local programs in 42 States find FIMR a powerful tool to help reduce infant mortality, including understanding issues related to preterm delivery. For over 20 years, ACOG has partnered with the Maternal and Child Health Bureau to sponsor the designated resource center for FIMR Programs, the National FIMR Program. ACOG supports \$.5 million in fiscal year 2014 for HRSA to increase the number of Healthy Start programs that use FIMR.

The Safe Motherhood Initiative at CDC works with State health departments to collect information on pregnancy-related deaths, track preterm births, and improve maternal outcomes. The Initiative also promotes preconception care, a key to reducing the risk of preterm birth. For fiscal year 2014, we recommend a sustained funding level of at least \$44 million for the Safe Motherhood Program, and reinstatement of the preterm birth sub-line at \$2 million to ensure continued support for preterm birth research, as authorized by the PREEMIE Act.

State and regional quality improvement initiatives encourage use of evidence-based quality improvement projects across hospitals and medical practices to reduce the rate of maternal and neonatal mortality and morbidity. For example, under the Ohio Perinatal Quality Collaborative, started in 2007 with funding from CDC, 21 OB teams in 25 hospitals have decreased scheduled deliveries between 36 and 39 weeks gestation, in accordance with ACOG guidelines, significantly reducing preterm births. According to a study conducted by Avalere, the estimated savings from initiatives aimed at reducing elective inductions pre-39 weeks ranges from \$2.4 million to \$9 million a year. S. 425, the Quality Care for Moms and Babies Act, would build on these efforts by providing resources to States to develop and grow mater-

nity and perinatal quality collaboratives, and supporting the development and implementation of additional maternity care quality measures in Medicaid and CHIP. ACOG urges you to provide sufficient resources to HHS to help States expand upon or establish maternity and perinatal care quality collaborative programs.

Again, we would like to thank the Committee for its consideration of funding for programs to improve women's health, and we urge you to consider our MOMS Initiative in fiscal year 2014.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PHYSICIANS

The American College of Physicians (ACP) is pleased to submit the following statement for the record on its priorities, as funded under the U.S. Department of Health & Human Services, for fiscal year 2014. ACP is the largest medical specialty organization and the second-largest physician group in the United States. ACP members include 133,000 internal medicine specialists (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness.

As the subcommittee begins deliberations on appropriations for fiscal year 2014, ACP is urging funding for the following proven programs to receive appropriations from the subcommittee:

- Title VII, Section 747, Primary Care Training and Enhancement, at no less than \$71 million;
- National Health Service Corps, \$893,456,433 in discretionary funding, in addition to the \$305 million in enhanced funding through the Community Health Centers Fund;
- National Health Care Workforce Commission, \$3 million;
- Agency for Healthcare Research and Quality, \$434 million; and
- Centers for Medicare and Medicaid Services, Marketplace Operations, \$803.5 million.

The United States is facing a growing shortage of physicians in key specialties, most notably in general internal medicine and family medicine—the specialties that provide primary care to most adult and adolescent patients. With enactment of the Affordable Care Act (ACA), we expect the demand for primary care services to increase with the addition of 27 million Americans receiving access to health insurance, once the law is fully implemented. Current projections indicate there will be a shortage of up to 44,000 primary care physicians for adults, even before the increased demand for health care services that will result from near universal coverage is taken into account (Colwill JM, Cultice JM, Kruse RL. Will generalist physician supply meet demands of an increasing and aging population? *Health Aff (Millwood)*. 2008 May-Jun;27(3):w232–41. Epub 2008 Apr 29. Accessed at <http://content.healthaffairs.org/content/27/3/w232.full> on 14 January 2011.). Without critical funding for vital workforce programs, this physician shortage will only grow worse. A strong primary care infrastructure is an essential part of any high-functioning healthcare system, with over 100 studies showing primary care is associated with better outcomes and lower costs of care (http://www.acponline.org/advocacy/where_we_stand/policy/primary_shortage.pdf).

The health professions education programs, authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA), support the training and education of health care providers to enhance the supply, diversity, and distribution of the health care workforce, filling the gaps in the supply of health professionals not met by traditional market forces, and are critical to help institutions and programs respond to the current and emerging challenges of ensuring all Americans have access to appropriate and timely health services. Within the Title VII program, we urge the subcommittee to fund the program the Section 747, Primary Care Training and Enhancement at \$71 million, in order to maintain and expand the pipeline of primary care production and training. The Section 747 program is the only source of Federal training dollars available for general internal medicine, general pediatrics, and family medicine. For example, general internists, who have long been at the frontline of patient care, have benefitted from Title VII training models that promoted interdisciplinary training that helped prepare them to work with other health professionals, such as physician assistants, patient educators and psychologists. Without a substantial increase of funding, HRSA will not be able to carry out a competitive grant cycle for the third year in a row for physician training; the Nation needs new initiatives relating to increased training in inter-professional care, the patient-centered medical home, and other new competencies required in our developing health system.

The College urges \$893,456,433 in appropriations for the National Health Service Corps (NHSC), the amount authorized for fiscal year 2014 under the ACA; this is in addition to the \$305 million in enhanced funding the Health and Human Services Secretary has been given the authority to provide to the NHSC through the Community Health Care Fund. Since enactment of the ACA, the NHSC has awarded over \$900 million in scholarships and loan repayment to health care professionals to help expand the country's primary care workforce and meet the health care needs of communities across the country and there are nearly three times the number of NHSC clinicians working in communities across America than there were 3 years ago, increasing Americans' access to health care. With field strength of nearly 10,000 clinicians, NHSC members are providing culturally competent care to more than 10.4 million people at nearly 14,000 NHSC-approved health care sites in urban, rural, and frontier areas. The increase in funds must be sustained to help address the health professionals' workforce shortage and growing maldistribution. The programs under NHSC have proven to make an impact in meeting the health care needs of the underserved, and with more appropriations, they can do more.

We urge the subcommittee to fully fund the National Health Care Workforce Commission, as authorized by the ACA, at \$3 million. The Commission is authorized to review current and projected health care workforce supply and demand and make recommendations to Congress and the Administration regarding national health care workforce priorities, goals, and policies. Members of the Commission have been appointed but have not been able to do any work, due to a lack of funding. The College believes the Nation needs sound research methodologies embedded in its workforce policy to determine the Nation's current and future needs for the appropriate number of physicians by specialty and geographic areas; the work of the Commission is imperative to ensure Congress is creating the best policies for our Nation's needs.

The Agency for Healthcare Research and Quality (AHRQ) is the leading public health service agency focused on health care quality. AHRQ's research provides the evidence-based information needed by consumers, providers, health plans, purchasers, and policymakers to make informed health care decisions. The College is dedicated to ensuring AHRQ's vital role in improving the quality of our Nation's health and recommends a budget of \$434 million. This amount will allow AHRQ to help providers help patients by making evidence-informed decisions, fund research that serves as the evidence engine for much of the private sector's work to keep patients safe, make the healthcare market place more efficient by providing quality measures to health professionals, and ultimately, help transform health and health care.

Finally, ACP is supportive of the President's request for \$803.5 million for the Centers for Medicare and Medicaid Services, Marketplace Operations in order to become fully operational by 2014 and carry out their duties as necessary. Such funding will allow the Federal Government to administer the insurance exchange, as authorized by the ACA, if a State declines to establish an exchange that meets Federal requirements. As of March 7, HHS has approved 24 States and the District of Columbia to fully or partially run their State's exchange, leaving 26 States which have not met approval or who have declined to run their own State exchange. If the subcommittee decides to deny the requested funds, it may make it much more difficult for the Federal Government to organize a federally-facilitated exchange in those States, raising questions about where and how their residents would get coverage. It is ACP's belief that all legal Americans—regardless of income level, health status, or geographic location—must have access to affordable health insurance.

In conclusion, the College is keenly aware of the fiscal pressures facing the subcommittee today, but strongly believes the United States must invest in these programs in order to achieve a high performance health care system and build capacity in our primary care workforce and public health system. The College greatly appreciates the support of the subcommittee on these issues and looks forward to working with Congress as you begin to work on the fiscal year 2014 appropriations process.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) urges the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing an increase of \$5 million in fiscal year 2014 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act. ACPM also supports the recommendation of the Health Professions and Nursing Education Coa-

lition that \$520 million be appropriated in fiscal year 2014 to support all health professions and nursing education and training programs authorized under Titles VII and VIII of the Public Health Service Act.

In today's healthcare environment, the tools and expertise provided by preventive medicine physicians play an integral role in ensuring effective functioning of our Nation's public health system. These tools and skills include the ability to deliver evidence-based clinical preventive services, expertise in population-based health sciences, and knowledge of the social and behavioral determinants of health and disease. These are the tools employed by preventive medicine physicians who practice in public health agencies and in other healthcare settings where improving the health of populations, enhancing access to quality care, and reducing the costs of medical care are paramount. As the body of evidence supporting the effectiveness of clinical and population-based interventions continues to expand, so does the need for specialists trained in preventive medicine.

Organizations across the spectrum have recognized the growing demand for preventive medicine professionals. The Institute of Medicine released a report in 2007 calling for an expansion of preventive medicine training programs by an "additional 400 residents per year," and the Accreditation Council on Graduate Medical Education (ACGME) recommends increased funding for preventive medicine residency training programs. Additionally, the Association of American Medical Colleges released statements in 2011 that stressed the importance of incorporating behavioral and social sciences in medical education as well as announcing changes to the Medical College Admission Test that would test applicants on their knowledge in these areas. Such measures strongly indicate increasing recognition of the need to take a broader view of health that goes beyond just clinical care—a view that is a unique focus and strength of preventive medicine residency training.

In fact, preventive medicine is the only one of the 24 medical specialties recognized by the American Board of Medical Specialties that requires and provides training in both clinical medicine and public health. Preventive medicine physicians possess critical knowledge in population and community health issues; disease and injury prevention; disease surveillance and outbreak investigation; and public health research. They are well versed in leading collaborative efforts to improve health that include stakeholder groups from all aspects of an issue—including community, industry, healthcare provider, academic, payer, and government organizations—in addressing both healthcare-related and social and behavioral determinants of health. Such diversity also illustrates the value preventive medicine physicians offer to many different sectors, industries, and organizations.

According to the Health Resources and Services Administration (HRSA) and health workforce experts, there are personnel shortages in many public health occupations, including epidemiologists, biostatisticians, and environmental health workers among others. According to the 2012 Physician Specialty Data Book released by the Association of American Medical Colleges, preventive medicine had one of the biggest decrease (–25 percent) in the number of first-year ACGME residents and fellows between 2005 and 2010. ACPM is deeply concerned about the shortage of preventive medicine-trained physicians and the ominous trend of even fewer training opportunities. This deficiency in physicians trained to carry out core public health activities will lead to major gaps in the expertise needed to deliver clinical prevention and community public health. The impact on the health of those populations served by HRSA may be profound.

Despite being recognized as an underdeveloped national resource and in shortage for many years, physicians training in the specialty of Preventive Medicine are the only medical residents whose graduate medical education (GME) costs are not supported by Medicare, Medicaid or other third party insurers. Training occurs outside hospital-based settings and therefore is not financed by GME payments to hospitals. Both training programs and residency graduates are rapidly declining at a time of unprecedented national, State, and community need for properly trained physicians in public health and disaster preparedness, prevention-oriented practices, quality improvement, and patient safety.

Currently, residency programs scramble to patch together funding packages for their residents. Limited stipend support has made it difficult for programs to attract and retain high-quality applicants. Support for faculty and tuition has been almost non-existent. Directors of residency programs note that they receive many inquiries about and applications for training in preventive medicine; however, training slots often are not available for those highly qualified physicians who are not directly sponsored by an outside agency or who do not have specific interests in areas for which limited stipends are available (such as research in cancer prevention).

HRSA—as authorized in Title VII of the Public Health Service Act—is a critical funding source for several preventive medicine residency programs, as it represents

the largest Federal funding source for these programs. HRSA funding (\$3.8 million in fiscal year 2013) currently supports only 49 preventive medicine residents across 9 residency training programs. An increase of \$5 million will allow HRSA to support nearly 60 new preventive medicine residents.

Of note, the preventive medicine residency programs directly support the mission of the HRSA health professions programs by facilitating practice in underserved communities and promoting training opportunities for underrepresented minorities:

- Thirty-five percent of HRSA-supported preventive medicine graduates practice in medically underserved communities, a rate of almost 3.5 times the average for all health professionals. These physicians are meeting a critical need in these underserved communities.
- Nearly one-fifth of preventive medicine residents funded through HRSA programs are under-represented minorities, which is almost twice the average of minority representation among all health professionals.
- Fourteen percent of all preventive medicine residents are under-represented minorities, the largest proportion of any medical specialty.

In addition to training under-represented minorities and generating physicians who work in medically underserved areas, preventive medicine residency programs equip our society with health professionals and public health leaders who possess the tools and skills needed in the fight against the chronic disease epidemic that is threatening the future of our Nation's health and prosperity. Correcting the root causes of this critical problem of chronic diseases will require a multidisciplinary approach that addresses issues of access to healthcare; social and environmental influences; and behavioral choices. ACPM applauds the initiation of programs such as the Community Transformation Grant that take this broad view of the determinants of chronic disease. However, any efforts to strengthen the public health infrastructure and transform our communities into places that encourage healthy choices must include measures to strengthen the existing training programs that help produce public health leaders.

Many of the leaders of our Nation's local and State health departments are trained in preventive medicine. Their unique combination of expertise in both medical knowledge and public health makes them ideal choices to head the fight against chronic disease as well as other threats to our Nation's health. Their contributions are invaluable. Investing in the residency programs that provide physicians with the training and skills to take on these leadership positions is an essential part of keeping Americans healthy and productive. As such, the American College of Preventive Medicine urges the Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee to reaffirm its support for training preventive medicine physicians and other public health professionals by providing an increase of \$5 million in fiscal year 2014 for preventive medicine residency training under the public health and preventive medicine line item in Title VII of the Public Health Service Act.

PREPARED STATEMENT OF THE AMERICAN DENTAL EDUCATION ASSOCIATION

The American Dental Education Association (ADEA), on behalf of all 66 U.S. dental schools, 700 dental residency training programs, nearly 600 allied dental programs, as well as more than 12,000 faculty who educate and train the nearly 50,000 students and residents attending these institutions, submits this statement for the record and for your consideration as you begin to prioritize fiscal year 2014 appropriation requests. ADEA urges you to preserve the funding and fundamental structure of Federal programs that provide prevention of dental disease, access to oral health care for underserved populations, and access to careers in dentistry and oral health services. It is at these academic dental institutions that future practitioners and researchers gain their knowledge, where the majority of dental research is conducted, and where significant dental care is provided. Services are provided through campus and offsite dental clinics where students and faculty provide patient care to the uninsured and underserved populations. However, in order to continue to provide these services, there must be adequate funding. Therefore, it is critical that funding for oral health care, delivery of services, and research be preserved in order to ensure the level of care that is necessary for all segments of the population.

We are asking the committee to maintain adequate funding for the dental programs in Title VII of the Public Health Service Act; the National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR); the Dental Health Improvement Act; Part F of the Ryan White HIV/AIDS Treatment and Modernization Act; the Dental Reimbursement Program and the Community-Based Dental Partnerships Program; and State-Based Oral Health Pro-

grams at the Centers for Disease Control and Prevention (CDC). These programs enhance and sustain State oral health departments, fund public health programs proven to prevent oral disease, fund research to eradicate dental disease, and fund programs to develop an adequate workforce of dentists with advanced training to serve all segments of the population including the underserved, the elderly, and those suffering from chronic and life-threatening diseases.

\$32 million for Primary Oral Healthcare Workforce Improvements (HHS)

The dental programs in Title VII, Section 748 of the Public Health Service Act that provide training in general, pediatric, and public health dentistry and dental hygiene are critical. Support for these programs will help to ensure there will be an adequate oral health care workforce to care for the American public. The funding supports pre-doctoral oral health education and postdoctoral pediatric, general, and public health dentistry training. The investment that Title VII makes not only helps to educate dentists and dental hygienists, but also expands access to care for underserved communities.

Additionally, Section 748 addresses the shortage of professors in dental schools with the dental faculty loan repayment program and faculty development courses for those who teach pediatric, general, or public health dentistry or dental hygiene. There are currently almost 300 open faculty positions in dental schools. These two programs provide schools with assistance in recruiting and retaining faculty. ADEA is increasingly concerned that with projected restrained funding, the oral health research community will not be able to grow and that the pipeline of new researchers will be inadequate to the future need.

Title VII Diversity and Student Aid programs play a critical role in helping to diversify the health profession's student body and thereby the health care workforce. For the last several years, these programs have not received adequate funding to sustain the progress that is necessary to meet the challenges of an increasingly diverse U.S. population. The ADEA is most concerned that the Administration did not request any funds for the Health Careers Opportunity Program (HCOP). This program provides a vital source of support for oral health professionals serving underserved and disadvantaged patients by providing a pipeline for such individuals to learn about careers in health care generally and dentistry specifically that is not available through other workforce programs.

\$15 million for Part F of the Ryan White HIV/AIDS Treatment and Modernization Act: Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program

Patients with compromised immune systems are more prone to oral infections like periodontal disease and tooth decay. By providing reimbursement to dental schools and schools of dental hygiene, the Dental Reimbursement Program (DRP) provides access to quality dental care for people living with HIV/AIDS while simultaneously providing educational and training opportunities to dental residents, dental students, and dental hygiene students who deliver the care. DRP is a cost-effective Federal/institutional partnership that provides partial reimbursement to academic dental institutions for costs incurred in providing dental care to people living with HIV/AIDS. This program is only reimbursing dental schools for the unreimbursed costs at 36.5 percent of those costs, continuing the shift of the cost burden to the schools. This path is not sustainable to provide the necessary care.

\$450 million for the National Institute of Dental and Craniofacial Research (NIDCR)

Discoveries stemming from dental research have reduced the burden of oral diseases, led to better oral health for millions of Americans, and uncovered important associations between oral and systemic health. Dental researchers are poised to make breakthroughs that can result in dramatic progress in medicine and health, such as repairing natural form and function to faces destroyed by disease, accident, or war injuries; diagnosing systemic disease from saliva instead of blood samples; and deciphering the complex interactions and causes of oral health disparities involving social, economic, cultural, environmental, racial, ethnic, and biological factors. Dental research is the underpinning of the profession of dentistry. With grants from NIDCR, dental researchers in academic dental institutions have built a base of scientific and clinical knowledge that has been used to enhance the quality of the Nation's oral health and overall health.

Also, dental scientists are putting science to work for the benefit of the health care system through translational research, comparative effectiveness research, health information technology, health research economics, and further research on health disparities.

\$19 million for the Division of Oral Health at the Centers for Disease Control and Prevention (CDC)

The CDC Division of Oral Health expands the coverage of effective prevention programs. The program increases the basic capacity of State oral health programs to accurately assess the needs of the State, organize and evaluate prevention programs, develop coalitions, address oral health in State health plans, and effectively allocate resources to the programs. This strong public health response is needed to meet the challenges of oral disease affecting children and vulnerable populations.

The level in fiscal year 2013 and the request for fiscal year 2014 are below the level needed to adequately sustain an appropriately staffed State dental program, provide a robust surveillance system to monitor and report disease, and support State efforts with other governmental, non-profit, and corporate partners. We look forward to sharing information with the committee in the coming weeks about the impact that the current path of funding will have on the overall health and preparedness of the Nation's States and communities.

Thank you for your consideration of this request. ADEA looks forward to working with you to ensure the continuation of congressional support for these critical programs. Please feel free to use us as a resource on any issue affecting dental education. Please contact Yvonne Knight, J.D., Senior Vice President for Advocacy and Governmental Relations at knighy@adea.org.

We look forward to working with you on the many issues of mutual concern.

PREPARED STATEMENT OF THE AMERICAN DENTAL HYGIENISTS' ASSOCIATION

On behalf of the American Dental Hygienists' Association (ADHA), thank you for the opportunity to submit testimony regarding appropriations for fiscal year 2014. ADHA appreciates the subcommittee's past support of programs that seek to improve the oral health of Americans and to bolster the oral health workforce. Oral health is a part of total health and authorized oral health care programs require appropriations support in order to increase the accessibility of oral health services, particularly for the underserved. ADHA urges \$32 million for Title VII Program Grants to expand and educate the dental workforce; ADHA urges that the block on funding for Section 340G-1 of the Public Health Service Act—a much-needed dental workforce demonstration program—be lifted and that \$10 million be appropriated; ADHA joins other oral health organizations in support for continued funding of the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program established under the Ryan White HIV/AIDS Treatment and Modernization Act (\$14 million for fiscal year 2014) as well as block grants offered by HRSA's Maternal Child Health Bureau (\$8 million for fiscal year 2014). ADHA also supports full funding for community health centers, and urges HRSA be directed to further bolster the delivery of oral health services at community health centers, including through the use of new types of dental providers. ADHA urges \$5 million for the CDC Oral Health Prevention and Education Campaign; ADHA urges funding sufficient so that all States have a school-based sealant program; ADHA urges at least \$25 million for oral health programming at CDC; ADHA urges \$20 million for Dental Health Improvement Grants. ADHA also urges funding of \$450 million for NIDCR.

ADHA is the largest national organization representing the professional interests of more than 150,000 licensed dental hygienists across the country. In order to become licensed as a dental hygienist, an individual must graduate from an accredited dental hygiene education program and successfully complete a national written and a State or regional clinical examination. Dental hygienists are primary care providers of oral health services and are licensed in each of the fifty States. Hygienists are committed to improving the Nation's oral health, a fundamental part of overall health and general well-being. In the past decade, the link between oral health and total health has become more apparent and the significant disparities in access to oral health care services have been well documented. At this time, when 130,000 million Americans struggle to obtain the oral health care required to remain healthy, Congress has a great opportunity to support oral health prevention, infrastructure and workforce efforts that will make care more accessible and cost-effective. ADHA urges funding of all authorized oral health programs and describes some of the key oral health programs below:

HRSA—Title VII Program Grants to Expand and Educate the Dental Workforce—Fund at a level of \$32 million in fiscal year 2014

A number of existing grant programs offered under Title VII support health professions education programs, students, and faculty. ADHA is pleased dental hygien-

ists are recognized as primary care providers of oral health services and are included as eligible to apply for several grants offered under the “General, Pediatric, and Public Health Dentistry” grants. With millions more Americans eligible for dental coverage in coming years, it is critical that the oral health workforce is bolstered. Dental and dental hygiene education programs currently struggle with significant shortages in faculty and there is a dearth of providers pursuing careers in public health dentistry and pediatric dentistry. Securing appropriations to expand the Title VII grant offerings to additional dental hygienists and dentists will provide much needed support to programs, faculty, and students in the future. ADHA recommends funding at a level of \$32 million for fiscal year 2014.

HRSA—Alternative Dental Health Care Provider Demonstration Project Grants—

Fund at a level of \$10 million in fiscal year 2014

Congress recognized the need to improve the oral health care delivery system when it authorized the Alternative Dental Health Care Provider Demonstration Grants, Section 340G–1 of the Public Health Service Act. The Alternative Dental Health Care Providers Demonstration Grants program is a Federal grant program that recognizes the need for innovations to be made in oral health care delivery to bring quality care to the underserved by pilot testing new models. Dental workforce expansion is one of many areas that need to be addressed as we move forward with efforts to increase access to oral health care services to those who are currently not able to obtain the care needed to maintain a healthy mouth and body. The authorizing statute makes clear that pilots must “increase access to dental care services in rural and underserved communities” and comply with State licensing requirements. Such new providers are already authorized in Minnesota and are under consideration in Connecticut, Vermont, Kansas, Maine, New Hampshire, Washington State and several other States. The fiscal year 2013 appropriations bill currently funding the Department of Health and Human Services includes language designed to block funding for this important demonstration program. We seek your leadership in removing this unjustified prohibition on funding for the Alternative Dental Health Care Providers Demonstration Grants. ADHA, along with more than 60 other oral health care organizations, advocated for funding of this important program. Without the appropriate supply, diversity and distribution of the oral health workforce, the current oral health access crisis will only be exacerbated. ADHA recommends funding at a level of \$10 million for fiscal year 2014 to support these vital demonstration projects.

HRSA—Dental Health Improvement Grants—

Fund at a level of \$20 million in fiscal year 2014

HRSA administered dental health improvement grants are an important resource for States to have available to develop and carry out State oral health plans and related programs. Past grantees have used funds to better utilize the existing oral health workforce to achieve greater access to care. Previously awarded grants have funded efforts to increase diversity among oral health providers in Wisconsin, promote better utilization of the existing workforce including the extended care permit (ECP) dental hygienist in Kansas, and in Virginia implement a legislatively directed pilot program to allow patients to directly access dental hygiene services. ADHA supports funding of HRSA dental health improvement grants at a level of \$20 million for fiscal year 2014.

CDC—Oral Health Prevention and Education Campaign—

Fund at a level of \$5 million in fiscal year 2014

A targeted national campaign led by the Centers for Disease Control (CDC) to educate the public, particularly those who are underserved, about the benefits of oral health prevention could vastly improve oral health literacy in the country. While significant data has emerged over the past decade drawing the link between oral health and systemic diseases like diabetes, heart disease, and stroke, many remain unaware that neglected oral health can have serious ramifications to their overall health. Data is also emerging to highlight the role that poor oral health in pregnant women has on their children, including a link between periodontal disease and low-birth weight babies. ADHA is pleased that the CDC has begun the development of an oral health communication plan and ADHA advocates an allocation of \$5 million in fiscal year 2014 to further a national oral health prevention and education campaign and to ensure that CDC’s media center has the resources needed to make oral health education material readily available.

*CDC—School-Based Sealant Programs—**Fund at a level sufficient to ensure school-based sealant programs in all 50 States*

Sealants have long-proven to be low-cost and effective in preventing dental caries (cavities), particularly in children. Despite this proven prevention capacity, dental caries remains the most common childhood disease, five times more common than asthma, and more than half of all children age 5–9 have a cavity or filling. The CDC noted that data collected in evaluations of school-based sealant programs indicates the programs are effective in stopping and preventing dental decay. CDC data show that the 60 percent increase in the delivery of school-based sealants in those States with CDC funding saved an estimated \$1 million in Medicaid dental expenditures. Significant progress has been made in developing best practices for school-based sealant programs, yet most States lack well developed programs as a result of funding shortfalls. ADHA encourages the transfer of funding from the Public Health and Prevention Fund sufficient to allow CDC to meaningfully fund school-based sealant programs in all 50 States in fiscal year 2014.

*CMS—Oral Health Access—**Given the dearth of dentists, encourage CMS to continue its efforts to improve access to pediatric oral health services provided by non-dentists, including dental hygienists and mid-level dental providers*

ADHA commends the Center for Medicare and Medicaid Services (CMS) for its work on the Department wide Oral Health Initiative and its continuing efforts to improve access to pediatric oral health services. These efforts are vital because, as the Center for Medicaid and CHIP Services noted in an April 18, 2013 Informational Bulletin, fewer than half of Medicaid-enrolled children nationally are receiving at least one preventive oral health service in a year, and there remains a wide variation across States. CMS noted in its fiscal year 2014 budget justification that, in response to report language in the fiscal year 2013 appropriations bill, that it will issue a State Medicaid Director letter in late 2013 providing a general clarification of CMS policy allowing States to reimburse for services provided by dental hygienists outside of a dental office without a prior exam or pre-authorization by a dentist. This letter should also make clear that CMS does not require dentist supervision of dental hygienists.

*CDC—Oral Health Programming—**Fund at a level of \$25 million in fiscal year 2014*

ADHA joins with others in the dental community in urging \$25 million for oral health programming within the Centers for Disease Control. This funding level will enable CDC to continue its vital work to control and prevent oral disease, including vital work in community water fluoridation. Federal grants to facilitate improved oral health leadership at the State level, support the collection and synthesis of data regarding oral health coverage and access, promote the integrated delivery of oral health and other medical services, enable States to innovate new types of oral health programs and promote a data-driven approach to oral health programming. ADHA advocates for \$25 million in funding for grants to improve and support oral health infrastructure and surveillance.

*NIH—National Institute of Dental and Craniofacial Research—**Fund at a level of \$450 million in fiscal year 2014*

The National Institute of Dental and Craniofacial Research (NIDCR) cultivates oral health research that has led to a greater understanding of oral diseases and their treatments and the link between oral health and overall health. Research breeds innovation and efficiency, both of which are vital to improving access to oral health care services and improved oral status of Americans in the future. ADHA joins with others in the oral health community to support NIDCR funding at a level of \$450 million in fiscal year 2014.

CONCLUSION

ADHA appreciates the difficult task Appropriators face in prioritizing and funding the many meritorious programs and grants offered by the Federal Government. In addition to the items listed, ADHA joins other oral health organizations in support for continued funding of the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnerships Program established under the Ryan White HIV/AIDS Treatment and Modernization Act (\$14 million for fiscal year 2014) as well as block grants offered by HRSA's Maternal Child Health Bureau (\$8 million for fiscal year 2014). ADHA also supports full funding for community health centers, and

urges HRSA be directed to further bolster the delivery of oral health services at community health centers, including through the use of new types of dental providers. ADHA remains a committed partner in advocating for meaningful oral health programming that makes efficient use of the existing oral health workforce and delivers high quality, cost-effective care.

PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

My name is John E. Anderson, M.D., President, Medicine and Science. Thank you for the opportunity to submit testimony on behalf of the American Diabetes Association (Association). As President of Medicine and Science for the Association, I represent the nearly 105 million American adults and children living with diabetes or prediabetes. Diabetes is a disabling, deadly, and growing epidemic. According to the CDC, one in three adults in our country—one in two among minority populations—will have diabetes in 2050 if present trends continue.

This is an unacceptable future that our country cannot afford, but it is avoidable. For fiscal year 2014, the Association urges the subcommittee to make a substantial investment in research and prevention efforts to find a cure, and improve the lives of those living with, or at risk for, diabetes. We ask the subcommittee to provide \$2.216 billion for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH), \$86.3 million for the Division of Diabetes Translation (DDT) at Centers for Disease Control and Prevention (CDC), and \$20 million in funding for the National Diabetes Prevention Program at CDC.

I care for patients with diabetes every day in my practice in Nashville, Tennessee, and I can testify to the tremendous need for a much deeper Federal investment in diabetes research and prevention programs. Nearly 26 million Americans have diabetes, and another 79 million have prediabetes, a condition putting them at high risk for developing diabetes. Every 17 seconds, someone in this country is diagnosed with diabetes. Today, 230 Americans with diabetes will undergo an amputation, 120 will enter end-stage kidney disease programs, and 55 will go blind from diabetes. When I walked through the Intensive Care Unit at my hospital, I was struck that half of the patients there have diabetes. Diabetes robs us of our limbs, our sight and our lives. It should not be ignored by anyone, including Congress and the Administration. My patients, and individuals with, and at risk for diabetes everywhere in this country deserve a different and brighter future.

In addition to the horrendous physical toll, diabetes is economically devastating to our country. A new report by the Association found the annual cost of diagnosed diabetes has skyrocketed by an astonishing 41 percent over the last 5 years—from \$174 billion per year in 2007 to \$245 billion in 2012. Approximately one out of every five health care dollars is spent caring for someone with diagnosed diabetes, while one in ten health care dollars is directly attributed to diabetes. An astonishing one of every three of Medicare dollars is associated with treating diabetes and its complications.

As the Nation's leading non-profit health organization providing diabetes research, information and advocacy, the American Diabetes Association believes that the alarming state of our Nation's diabetes epidemic justifies the critical need for increased Federal funding for diabetes research and prevention programs. We acknowledge the challenging economic climate and support fiscal responsibility, but our country cannot afford the consequences of failing to adequately fight this growing epidemic. Sequestration has only heightened our concern about the future of key diabetes programs at NIDDK and DDT. If we hope to leave our children a physically and fiscally healthy Nation, we can't afford to turn our backs on promising research providing the keys to preventing diabetes, better managing the disease, and bringing us closer to a cure. The rising tide of diabetes in America is daunting, but not insurmountable. The Association is pressing forward by supporting research and expanding education and awareness efforts, but we cannot do it alone. Congress must immediately and significantly step up its response to this epidemic.

BACKGROUND

Diabetes is a chronic disease that impairs the body's ability to utilize food. The hormone insulin, which is made in the pancreas, is needed for the body to change food into energy. In people with diabetes, either the pancreas does not create insulin, which is type 1 diabetes, or the body does not create enough insulin and/or cells are resistant to insulin, which is type 2 diabetes. If left untreated, diabetes results in too much glucose in the blood stream. Blood glucose levels that are too high or too low (as a result of medication to treat diabetes) can be life threatening in the

short term. In the long term, diabetes is the leading cause of kidney failure, new cases of adult-onset blindness, and non-traumatic lower limb amputations—as well as a leading cause of heart disease and stroke. Additionally, an estimated 18 percent of pregnancies are affected by gestational diabetes, a form of glucose intolerance diagnosed during pregnancy placing both mother and baby at risk. In those with prediabetes, blood glucose levels are higher than normal and reducing their risk of developing diabetes it is essential.

THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES AT NIH

NIDDK leads the way in supporting research across the country that moves us closer to a cure and better treatments for diabetes. Thanks to research supported by the NIDDK, people with diabetes now manage their disease with a variety of insulin formulations and regimens far superior to those used in decades past. For example, the continuous glucose monitor and insulin pumps many of my patients use allow them to better manage their blood glucose levels—and better pave the way to healthier futures.

Examples of NIDDK-funded breakthroughs include: new drug therapies for type 2 diabetes; the advent of modern treatment regimens that have reduced the risk of costly complications like heart disease, stroke, amputation, blindness and kidney disease; and ongoing development of the artificial pancreas, a closed looped system combining continuous glucose monitoring with insulin delivery.

While progress has been great, now is not the time to retreat from efforts that may bring new discoveries in the study of diabetes. Without increased funding, NIDDK will slow or halt promising research that would enable individuals with the disease to live healthier, more productive lives. The percentage of promising research proposals NIDDK was able to fund decreased last year and is expected to decrease again this year without additional funding. This is an ominous sign for the millions of American families affected by diabetes who continue to await the day when there are vastly improved treatments for diabetes and ultimately, a cure for the disease.

Overall fiscal year 2014 funding of \$2.216 billion would allow the NIDDK to support additional research to further improve prevention and treatment, and close in on a cure. For example, additional funding will support a new comparative effectiveness clinical trial testing different medications for type 2 diabetes. Additionally, NIDDK will be able to continue to support researchers studying how insulin-producing beta cells develop and function, with an ultimate goal of creating therapies for replacing damaged or destroyed beta cells in people with diabetes. Funding will also support a clinical trial testing therapies to prevent type 2 diabetes.

THE DIVISION OF DIABETES TRANSLATION (DDT) AT THE CDC

The prevalence of diabetes has increased dramatically in every State. The Federal Government's role in coordinating efforts to prevent diabetes and its serious complications has never been more essential. With this in mind, the Association remains very concerned that DDT's funding has not kept pace with the magnitude of the growing diabetes epidemic. We urge the Federal investment in DDT programs be substantially increased to a minimum of \$86.3 million in fiscal year 2014.

Increased fiscal year 2014 funding is even more critical in light of the combined chronic disease grant application for State diabetes, heart disease, obesity, and school health programs, released by CDC in February 2013. While we think coordination across chronic disease programs at CDC is an important endeavor, Congress must ensure the needs of people with, and at risk for, diabetes are adequately addressed in this new funding process. Increased resources must be provided for this effort and delivery of primary, secondary, and tertiary diabetes prevention and performance measures must be a prime focus of combined grant activities in every State.

The DDT works to eliminate the preventable burden of diabetes through proven educational programs, best practice guidelines, and applied research. It performs important work in primary prevention of diabetes and in preventing its complications. Funding for the DDT must focus on maintaining State-based Diabetes Prevention and Control Programs (DPCPs), supporting the National Diabetes Education Program, defining the diabetes burden through the use of public health surveillance, and translating research findings into clinical and public health practice. For example, the DPCPs, located in all 50 States, the District of Columbia, and all U.S. territories, work to prevent diabetes, lower blood glucose and cholesterol levels, and reduce diabetes-related emergency room visits and hospitalizations. This work is designed to improve education and awareness of diabetes by engaging health providers, health systems and community-based organizations to ensure these outcomes

are achieved. DDT funding also supports translational research like the SEARCH for Diabetes in Youth study, a joint NIDDK-DDT effort designed to determine the impact of type 2 diabetes in youth to improve prevention efforts aimed at young people.

With additional fiscal year 2014 funding, the DDT will be able to expand the efforts of DPCPs to improve primary, secondary and tertiary prevention efforts at the State and local levels. Investing in DDT will also enable community-based organizations in urban and rural areas to reduce risk factors for diabetes in populations bearing a disproportionate burden of the disease through two valuable programs: the National Program to Eliminate Diabetes-Related Disparities in Vulnerable Populations and the Native Diabetes Wellness Program, which delivers effective health promotion activities tailored to American Indian/Native Alaskan communities. Increased funding for DDT will also allow it to expand its translational research to improve public health interventions, such as the Translating Research Into Action for Diabetes (TRIAD) study, a national, multicenter research effort to provide practical information on how to improve care of individuals with diabetes in managed-care settings.

THE NATIONAL DIABETES PREVENTION PROGRAM (CDC)

The Association is alarmed that 79 million Americans have prediabetes and are on the cusp of a type 2 diabetes diagnosis. Thankfully, the National Diabetes Prevention Program supports a national network of community-based sites where trained staff provides those at high risk for diabetes with cost-effective, group-based lifestyle intervention programs. We urge Congress to provide \$20 million for the National Diabetes Prevention Program in fiscal year 2014 to continue its nationwide expansion. The program is a proven means of combating a growing epidemic, and research has shown it can reduce the risk of type 2 diabetes by 58 percent for individuals with prediabetes—at a cost of only about \$300 per participant. Currently, there are over 200 CDC recognized programs and the largest program, run by the Y-USA, has 420 sites across the country. The National Diabetes Prevention Program began with a successful NIDDK study in a clinical setting. Additional translational research was then done by NIDDK and DDT, proving the program also works in the less-costly community setting. This is exactly the program we should be bringing to scale if we hope to conquer our country's diabetes epidemic.

CONCLUSION

The Association is counting on Congress to significantly expand its investment at NIDDK and the DDT in fiscal year 2014, including the National Diabetes Prevention Program. We must change our country's future with regard to this devastating disease and hope, even in a difficult fiscal environment, the explosive growth in the financial and human tolls of diabetes will be reflected in your appropriations decisions. Thank you for the opportunity to submit this testimony. The Association looks forward to working with you to stop diabetes.

PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

Although major progress has been made in the battle against cardiovascular disease (CVD) and stroke, CVD remains our Nation's No. 1 and most costly killer of men and women, costing each year a projected \$313 billion in medical expenses and lost productivity. Stroke, alone, is our No. 4 killer, costing an estimated \$40 billion a year. Both remain major causes of disability.

Today, an estimated 83 million U.S. adults suffer from CVD and a recent study projects that by the year 2030, more than 40 percent of U.S. adults will live with CVD at a cost exceeding \$1 trillion annually. However, CVD and stroke research, prevention and treatment remain woefully underfunded and there is no steady stream of funding for the National Institutes of Health to mount a long-term, aggressive campaign against these terrible burdens on society.

The current Federal budget dilemma makes a bad situation worse. The sequestration and funding the Government under a continuing resolution endanger the health of tens of millions of CVD sufferers and threaten to undermine our struggling economy and global competitiveness. It is imperative that Congress provide stable and sustained funding for CVD and stroke research, prevention and treatment programs. The Nation's physical and fiscal health are at stake.

FUNDING RECOMMENDATIONS: INVESTING IN THE HEALTH OF OUR NATION

Promising research that could stem the increase of heart disease and stroke risk factors remains unfunded. If Congress fails to capitalize on 50 years of progress, we will pay more in lives lost and health care costs. Our recommendations address the issues in a fiscally responsible way.

Capitalize on Investment for the National Institutes of Health (NIH)

NIH research helps prevent and cure disease, creates economic growth, fosters innovation, and preserves U.S. leadership in pharmaceuticals and biotechnology, and has transformed patient care. NIH is the primary funder of basic research—the starting point for all medical progress and an essential function of the Federal Government that the private sector cannot fill.

NIH produces major returns on investment by developing new technologies that create good-paying jobs. In fiscal year 2012, NIH created about 402,000 U.S. jobs and produced \$57.8 billion in economic activity. Each dollar NIH distributes in a grant returns \$2.21 in goods and services to the local community in just 1 year. Under sequestration, the NIH budget will be cut by 5 percent or \$1.6 billion, reducing its budget to 2007 levels, with an expected loss of 2,300 planned grants. Since NIH invests in every State and in 90 percent of congressional districts, 20,500 jobs will be lost and new economic activity will decline by \$3 billion. These cuts will compromise NIH's role as the world leader in medical research, delay treatments and cures as scientists are on the verge of breakthroughs, and dishearten early career investigators who may not return to science.

American Heart Association Advocates.—We ask Congress to appropriate \$32 billion, same as our request last year, for NIH to restore sequester cuts, improve health, spur our economy and innovation, and promote heart and stroke research.

Enhance Funding for NIH Heart and Stroke Research: A Proven and Wise Investment

Declining death rates from CVD and stroke are directly related to NIH research, with scientists on the cusp of discoveries that could lead to revolutionary treatments and even cures. In addition to saving lives, NIH research is cost-effective. For example, the first NIH tPA drug trial resulted in a 10-year net \$6.47 billion drop in stroke health care costs. Also, the Stroke Prevention in Atrial Fibrillation Trial 1 produced a 10-year net savings of \$1.27 billion.

Cardiovascular Disease Research: National Heart, Lung, and Blood Institute (NHLBI)

Although heart disease death rates have sharply fallen, there is still no cure for CVD and demand will only increase to find better ways for people to live healthy and productive lives with CVD. Stable and sustained NHLBI funding is essential to capitalize on investments that have discovered a gene variant linked to aortic valve disease; developed a new computer tomography scanner that provides better heart images with far less radiation; used genetics to identify and treat those at greatest risk of CVD; hastened drug development to reduce cholesterol and blood pressure; and created tailored strategies to treat, slow or prevent heart failure. Sustained funding will permit aggressive implementation of priority initiatives in the CVD strategic plan.

Stroke Research: National Institute of Neurological Disorders and Stroke (NINDS)

An estimated 795,000 Americans will suffer a stroke this year, and more than 129,000 will die. Many of the 7 million survivors face severe physical and mental disabilities and emotional distress. In addition to the physical and emotional toll, stroke will cost a projected \$40 billion in medical expenses and lost productivity this year. And the future looks bleak. One study projects stroke prevalence will increase 25 percent over the next 20 years, striking more than 10 million individuals with direct medical costs rising 238 percent over the same time.

Stable and sustained NINDS funding is required to advance the nine top priorities in stroke prevention, treatment and recovery research. They include: accelerating translation of preclinical animal models into clinical studies; preventing vascular cognitive impairment; expediting comparative effectiveness research trials; developing imaging biomarkers; expanding and integrating stroke trial networks; improving clot-busting treatments; achieving robust brain protection; targeting early stroke recovery; and using neural interface devices.

American Heart Association Advocates.—We recommend that NHLBI be funded at \$3.2 billion and NINDS at \$1.7 billion for fiscal year 2014.

Increase Funding for the Centers for Disease Control and Prevention (CDC)

Prevention is one of the strongest tools in the fight against CVD and stroke. In our summary of prevention cost-effectiveness and value, we found, for example, comprehensive worksite health programs have shown a \$3.27 cut in medical costs for each dollar spent in the first 12–18 months. Yet, proven prevention strategies are not being implemented due to scarce funds. In addition to conducting research and evaluation and developing a surveillance system, the Division for Heart Disease and Stroke Prevention manages Sodium Reduction Communities and the Paul Coverdell National Acute Stroke Registry. Also, DHDSP, with the Centers for Medicare and Medicaid Services, implements Million Hearts™ to prevent 1 million heart attacks and strokes in 5 years.

The DHDSP also manages WISEWOMAN that serves uninsured and under-insured, low-income women ages 40 to 64. It helps them avoid heart disease and stroke by providing preventive health services, referrals to local health care providers—as needed—and lifestyle counseling and interventions tailored to risk factors to promote lasting behavior change.

American Heart Association Advocates.—We join with the CDC Coalition in asking for \$7.8 billion for CDC’s “core programs.” AHA requests \$75 million for the DHDSP and \$37 million for WISEWOMAN. Also, we advocate for \$35 million of the Prevention and Public Health Fund be allocated for Million Hearts™ to execute a national blood pressure educational campaign targeted at the 37 million Americans with uncontrolled blood pressure.

Restore Funding for Rural and Community Access to Emergency Devices (AED) Program

About 90 percent of cardiac arrest victims die outside of a hospital. Yet, prompt CPR and defibrillation with an automated external defibrillator (AED) can more than double the chances of survival. Communities with comprehensive AED programs have survival rates approaching 40 percent, compared to the current less than 10 percent. HRSA’s Rural and Community AED Program provides competitive grants to States to buy AEDs, strategically place them, and train lay rescuers and first responders in their use. Due to this effort, almost 800 patients were saved between August 1, 2009 and July 31, 2010. But limited resources allowed only 6 percent of applicants to be funded and only 8 States received funds in fiscal year 2012.

American Heart Association Advocates.—We ask for a fiscal year 2014 appropriation of \$8.927 million to restore this life-saving AED program to fiscal year 2005 levels when 47 States were funded.

CONCLUSION

Cardiovascular disease and stroke continue to inflict a deadly, disabling and costly toll on Americans. Our funding recommendations for NIH, CDC and HRSA will save lives and cut rising health care costs. We urge Congress to seriously consider our proposals that represent a wise investment for our Nation and for the health and well-being of this and future generations.

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

This statement includes the fiscal year 2014 (fiscal year 2014) recommendations of the Nation’s Tribal Colleges and Universities (TCUs), in two areas of the Department of Education: Office of Postsecondary Education and Office of Vocational Education.

I. Higher Education Act Programs:

—*Strengthening Developing Institutions.*—Titles III and V of the Higher Education Act support institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. TCUs, funded under Title III–A Sec. 316, which are truly developing institutions, are providing quality higher education opportunities to some of the most rural, impoverished, and historically underserved areas of the country. The goal of HEA–Titles III/V programs is “to improve the academic quality, institutional management and fiscal stability of eligible institutions, in order to increase their self-sufficiency and strengthen their capacity to make a substantial contribution to the higher education resources of the Nation.” The TCU Title III–A program is specifically designed to address the critical, unmet needs of their American Indian students and communities, in order to effectively prepare them to succeed in a global, competitive workforce. Yet, in fiscal year 2011 this critical program was cut by over 11 percent and by another 4 percent in fiscal year 2012. The

TCUs urge the subcommittee to appropriate \$30 million in fiscal year 2014 for HEA Title III—A Section 316.

—*TRIO*.—Retention and support services are vital to achieving the national goal of having the highest percentage of college graduates globally by 2020. TRIO programs, such as Student Support Services and Upward Bound were created out of recognition that college access is not enough to ensure advancement and that multiple factors work to prevent the successful completion of higher education for many low-income and first-generation students and students with disabilities. Therefore, in addition to maintaining the maximum Pell Grant award level, it is critical that Congress also sustains student assistance programs such as Student Support Services and Upward Bound so that low-income and minority students have the support necessary to allow them to remain enrolled in and ultimately complete their postsecondary courses of study.

Pell Grants.—The importance of Pell Grants to TCU students cannot be overstated. A majority of TCU students receive Pell Grants, primarily because student income levels are so low and they have far less access to other sources of financial aid than students at State-funded and other mainstream institutions. Within the TCU system, Pell Grants are doing exactly what they were intended to do—they are serving the needs of the lowest income students by helping them gain access to quality higher education, an essential step toward becoming active, productive members of the workforce. However, last summer the Department of Education changed its regulations limiting Pell eligibility from 18 to 12 full-time semesters, without consideration of those already in the process of attaining a postsecondary degree. This change in policy will impede many TCU students from completing a postsecondary degree, which is widely recognized as being critical for access to, and advancement in, today's highly technical workforce.

Recent placement tests administered at TCUs to first-time entering students indicated that 64 percent required remedial math, 78 percent needed remedial writing, and 60 percent required remedial reading. These results clearly illustrate just how serious this new Pell Grant eligibility limit is to the success of TCU students in completing a postsecondary degree. Students requiring remediation can use as much as a full year of eligibility enhancing their math, and or reading/writing skills, thereby hampering their future postsecondary degree plans. A prior national goal was to provide access to quality higher education opportunities for all students regardless of economic means, at which TCUs have been extremely successful. While the new national goal is intending to produce graduates with postsecondary degrees by 2020, this policy does not advance that objective. On the contrary, the new regulations will cause many low-income students to once again abandon their dream of a postsecondary degree, as they will simply not have the means to pursue it. The goal of a well-trained technical workforce will be greatly compromised. This new policy evokes the adage “penny wise—pound foolish.” The TCUs urge the subcommittee to continue to fund this essential program at the highest possible level, and to direct the Secretary of Education to implement a process to waive the very restrictive 12 semester Pell Grant eligibility for TCU students.

II. Perkins Career and Technical Education Programs:

—*Tribally-Controlled Postsecondary Career and Technical Institutions*.—Section 117 of the Carl D. Perkins Career and Technical Education Act provides a competitively awarded grant opportunity for tribally chartered and controlled career and technical institutions. AIHEC requests \$8,200,000 to fund grants under Sec. 117 of the Perkins Act.

—*Native American Career and Technical Education Program (NACTEP)*.—NACTEP (Sec. 116) reserves 1.25 percent of appropriated funding to support American Indian career and technical programs. The TCUs strongly urge the subcommittee to continue to support NACTEP, which is vital to the continuation of career and technical education programs offered at TCUs that provide job training and certifications to remote reservation communities.

III. American Indian Adult and Basic Education (Office of Vocational and Adult Education): This program supports adult basic education programs for American Indians offered by State and local education agencies, Indian tribes, agencies, and TCUs. Despite the absence of funding, TCUs must find a way to continue to provide adult basic education classes for those American Indians that the present K–12 Indian education system has failed. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, even learn to read. There is an extensive need for adult basic educational programs, and TCUs must have adequate and stable funding to provide these essential activities. TCUs request that the subcommittee direct that \$8 million of the funds appropriated annually for the Adult Education State Grants be made available to make competitive awards to TCUs to help meet the growing demand

for adult basic education and remediation program services on their respective Reservations.

JUSTIFICATIONS FOR FISCAL YEAR 2014 APPROPRIATIONS REQUESTS FOR TCUS

Tribal colleges and our students are already being disproportionately impacted by ongoing efforts to reduce the Federal budget deficit and control Federal spending. The final fiscal year 2011 Continuing Resolution eliminated all of the Department of Housing and Urban Development's Minority Serving Institutions (MSIs) community-based programs, including a critical TCU-HUD facilities program. TCUs were able to maximize leveraging potential, often securing even greater non-Federal funding to construct and equip Head Start and early childhood centers; student and community computer laboratories and public libraries; and student and faculty housing in rural and remote communities where few or none of these facilities existed. Important STEM programs, operated by the National Science Foundation and NASA were cut, and for the first time since the NSF program was established in fiscal year 2001, no new TCU-STEM awards were made in fiscal year 2011. Additionally, TCUs and their students suffer the realities of cuts to programs such as GEAR-UP, TRIO, SEOG, and as noted earlier, are seriously impacted by the new highly restrictive Pell Grant eligibility criteria more profoundly than mainstream institutions of higher education, which can realize economies of scale due to large endowments, alternative funding sources, including the ability to charge higher tuition rates and enroll more financially stable students, and access to affluent alumni. The loss of opportunity that cuts to DoEd, HUD, and NSF programs represent to TCUs, and to other MSIs, is magnified by cuts to workforce development programs within the Department of Labor, nursing and allied health professions tuition forgiveness and scholarship programs operated by the Department of Health and Human Services, and an important TCU-based nutrition education program planned by USDA. Combined, these cuts strike at the most economically disadvantaged and health-challenged Americans.

We respectfully ask the members of the subcommittee for their continued investment in the Nation's TCUs and full consideration of our fiscal year 2014 appropriations needs and recommendations.

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION

Centers for Disease Control & Prevention <i>Increase overall CDC funding—\$7.8 billion</i>	National Institutes of Health <i>Increase overall NIH funding—\$32 billion</i>
Healthy Communities Program—\$52.8 million Office on Smoking and Health—\$212.36 million Asthma programs—\$28.435 million Environment and Health Tracking Network—\$35 million Tuberculosis programs—\$243 million Influenza Planning and Response—\$173.061 million NIOSH—\$292.588 million (discretionary) Prevention and Public Health Fund—Please Protect the Fund	National Heart, Lung and Blood Institute—\$3.214 billion National Cancer Institute—\$5.296 billion National Institute of Allergy and Infectious Diseases—\$4.689 billion National Institute of Environmental Health Sciences—\$717.9 million National Institute of Nursing Research—\$151.178 million National Institute on Minority Health & Health Disparities—\$288.678 million Fogarty International Center—\$72.864 million

The American Lung Association is pleased to present our recommendations for fiscal year 2014 (fiscal year 2014) to the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee. The public health and research programs funded by this committee will prevent lung disease and improve and extend the lives of millions of Americans. Founded in 1904 to fight tuberculosis, the American Lung Association is the oldest voluntary health organization in the United States. The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research.

The Public Health Infrastructure Cannot Support Further Cuts

The American Lung Association acknowledges and thanks the Committee for its commitment to maintaining investments in public health. The Lung Association is very concerned about the impact of cuts in the last 5 years to public health agencies, especially those resulting from sequestration.

The President's Budget for fiscal year 2014 proposes further cuts to critical to the Nation's public health infrastructure. The President's Budget contains another 3.7 percent in cut in budget authority for the Centers for Disease Control and Prevention and an 8.4 percent cut in program level (including the Prevention Fund and other categories) since fiscal year 2012. In the last four fiscal years, CDC budget authority has fallen by 14.8 percent and program level by 9.3 percent—a truly frightening prospect when considering the future of our Nation's public health agency.

Investments in prevention and wellness pay near- and long-term dividends for the health of the American people. A recent study on the California tobacco control program published in PLoS One showed this amazing result: for every dollar the State spent on the program, it saved \$55 in healthcare costs. In order to save healthcare costs in the long-term, investments must be made in proven public health interventions including tobacco control, asthma programs and TB infrastructure, particularly in light of recent sequestration cuts.

Lung Disease

Each year, close to 400,000 Americans die of lung disease. It is America's number three killer, responsible for one in every six deaths. More than 33 million Americans suffer from a chronic lung disease and it costs the economy an estimated \$106 billion each year. Lung diseases include: lung cancer, asthma, chronic obstructive pulmonary disease (COPD), tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease and sarcoidosis.

Improving Public Health and Maintaining Our Investment in Medical Research

The American Lung Association strongly supports increasing overall CDC funding to \$7.8 billion in order for CDC to carry out its prevention mission and to assure an adequate translation of new research into effective State and local public health programs. Congress must also maintain its commitment to medical research by increasing overall NIH funding to \$32 billion. While our focus is on lung disease research, we support increasing the investment in research across the entire NIH.

The Prevention and Public Health Fund

The American Lung Association has repeatedly stated its support for the Public Health and Prevention Fund and our fierce opposition to any attempts to divert or use these dollars for any purposes other than what was originally intended in the Affordable Care Act—which in part is to prevent and better manage devastating chronic diseases. The Committee must oppose any attempts to divert or use the Fund for any purposes other than what it was originally intended. The Prevention Fund provides funding to critical public health initiatives, like community programs that help people quit smoking, support groups for lung cancer patients, and classes that teach people how to avoid asthma attacks.

The Lung Association remains troubled that Prevention Fund dollars are being used to supplant public health funds rather than supplement them as originally intended. The intent of the Prevention Fund was to fund additional public health programs and initiatives—leading to additional health benefits—not to fund already existing ones. An example of this is the President's proposal to fund the Environmental and Health Tracking Network entirely with Prevention Fund dollars. This program was previously funded by budget authority. As the Prevention Fund dollars remain under threat and continue to be diverted for other purposes, added budget authority at CDC is even more important.

One high profile example of successful use of Prevention Fund dollars is CDC's Tips from Former Smokers campaign. The first phase of the campaign, which began in March 2012, resulted in hundreds of thousands of additional calls to 1-800-QUIT NOW and visits to smokefree.gov by smokers seeking help in quitting. CDC began re-airing the Tips ads in March 2013, and calls to 1-800-QUIT-NOW doubled in a majority of States. In April, new and extremely powerful ads in the Tips series began to air. The response from smokers seeking help to quit is tangible evidence of the Fund having a positive impact.

Tobacco Use

The American Lung Association recognizes the ongoing support of the Committee in investing in proven ways to reduce tobacco use. Tobacco use is the leading preventable cause of death in the United States, killing more than 443,000 people every year. Over 43 million adults and 1.9 million youth in the U.S. smoke. Annual health care and lost productivity costs total \$193 billion in the U.S. each year. Given the magnitude of the tobacco-caused disease burden and how much of it can be prevented, the CDC Office on Smoking and Health (OSH) should be much larger and better funded. Historically, Congress has failed to invest in tobacco control—even

though public health interventions have been scientifically proven to reduce tobacco use. This neglect cannot continue if the Nation wants to prevent disease, promote wellness and reduce healthcare costs. The American Lung Association requests \$212.36 million be appropriated to OSH for fiscal year 2014.

Lung Cancer

The American Lung Association thanks the Committee's support for and interest in the National Cancer Institute's Lung Cancer Screening Trial and its findings. Given the magnitude of lung cancer and the enormity of the death toll, the American Lung Association strongly recommends that the NIH and other Federal research programs commit additional resources to lung cancer. The National Lung Screening Trial showed promising results for a small segment of the population at high risk for developing lung cancer but more research must be done in order to see if others would similarly benefit.

Over 370,000 Americans are living with lung cancer. During 2012, more than 226,000 new cases of lung cancer were diagnosed—roughly 14 percent of all cancer diagnoses. It is the leading cause of cancer deaths, with a five year survival rate of only 16.3 percent. In 2009, there were 87,694 lung cancer deaths in men and 70,387 in women. Although the number of deaths among men has plateaued, the number is still rising among women. African Americans are more likely to develop and die from lung cancer than persons of any other racial group. We support a funding level of \$5.296 billion for the NCI and strongly urge more attention and focus on lung cancer.

Chronic Obstructive Pulmonary Disease (COPD)

COPD is the third leading cause of death in the U.S. It has been estimated that 13.1 million patients have been diagnosed with some form of COPD and as many as 24 million adults may suffer from its consequences. In 2009, 133,965 people in the U.S. died of COPD. The annual cost to the Nation for COPD in 2010 was projected to be \$49.9 billion. We strongly support funding the NHLBI and its lifesaving lung disease research program at \$3.214 billion. The American Lung Association also asks the Committee continue its support of the NHLBI working with the CDC and other appropriate agencies address COPD, including ongoing Federal efforts to better coordinate and implement Federal activities regarding COPD.

Asthma

Asthma is highly prevalent and expensive. More than 25 million Americans currently have asthma, of whom 7 million are children. Asthma prevalence rates are over 37 percent higher among African Americans than whites. Asthma is also the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. Asthma costs our healthcare system over \$50.1 billion annually and indirect costs from lost productivity add another \$5.9 billion, for a total of \$56 billion dollars annually. But teaching children and adults how to manage their asthma saves money. A study that appeared in the American Journal of Respiratory Critical Care found that for every dollar invested in asthma interventions, there was a \$35 benefit in healthcare cost savings and workdays lost.

The Lung Association was pleased to see that the President's fiscal year 2014 budget request did not again propose to merge the CDC's National Asthma Control Program with the Healthy Homes Program and slash its funding. The Lung Association thanks this Committee for its support of the National Asthma Control Program and asks for an appropriation of \$28.435 million (\$25.3 million for programmatic and \$3.1 million for the working capital fund) in fiscal year 2014. In addition, we recommend that the NHLBI receive \$3.214 billion and the NIAID receive \$4.689 billion, and that both agencies continue their research investments in cures and treatments for asthma.

Influenza

Public health experts warn that 209,000 Americans could die and 865,000 would be hospitalized if a moderate flu epidemic hits the U.S., which may be made worse because of sequestration. Current threats of the latest strain of "bird flu" in China are a good example of our needs in this area. According to the World Health Organization, the H7N9 virus has sickened 108 people and killed 22. Public health officials are tracking the victims closely to determine whether there is evidence of human-to-human transmission, which would be the precursor of a possible pandemic. This swift and thorough response would not be possible without public health infrastructure in place and ready to respond to threats. To prepare for a potential pandemic, the American Lung Association supports funding CDC's influenza planning and response efforts at \$173.061 million.

Tuberculosis (TB)

There are an estimated 10–15 million Americans who carry latent TB infection, and it is estimated that 10 percent of these individuals will develop active TB disease. In 2011, there were 10,528 cases of active TB reported in the U.S. While declining overall TB rates are good news, the emergence and spread of multi-drug resistant TB and totally-drug resistant TB also poses a significant public health threat. We request that Congress increase funding for tuberculosis programs at CDC to \$243 million for fiscal year 2014.

Additional Priorities

We strongly encourage improved disease surveillance and health tracking to better understand diseases like asthma. We support an appropriations level of \$35 million for the Environment and Health Outcome Tracking Network from budget authority instead of Prevention Fund dollars. We also strongly recommend at least \$52.8 million in funding for CDC's Healthy Communities Program. This program supports investments in communities to identify and improve policies and environmental factors influencing health and reduce the burden of chronic diseases.

CONCLUSION

Lung disease is a continuing, growing problem in the United States. It is America's number three killer, responsible for one in six deaths. Progress against lung disease is not keeping pace with progress against other major causes of death and more must be done. The level of support this committee approves for lung disease programs should reflect the urgency illustrated by the impact of lung disease.

PREPARED STATEMENT OF THE AMERICAN NATIONAL RED CROSS

Chairman Tom Harkin, Ranking Member Jerry Moran, and members of the subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative (the Initiative). The Initiative aims to reach elimination goals for measles, rubella and congenital rubella syndrome. The current UN goal is to reduce global measles deaths by 95 percent by 2015 compared to 2000 estimates, and three of six WHO regions have set rubella control or elimination targets. The Initiative is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved “spectacular”¹ results by supporting the vaccination of more than 1.1 billion children. Largely due to the Measles & Rubella Initiative, global measles mortality dropped 71 percent, from an estimated 548,000 deaths in 2000 to 158,000 in 2011 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 84 percent. About 430 children still die from measles each day from a virus that can be countered with an effective, inexpensive vaccine; and each year more than 110,000 children are born with congenital rubella syndrome. In May 2012, the 194 member States of the World Health Assembly resolved to endorse the Global Vaccine Action Plan, which affirmed the elimination of measles and rubella by 2020 in at least five of six WHO regions as global goals.

ESTIMATED NUMBER OF GLOBAL MEASLES DEATHS, 2000–2010
[In thousands]

	Number
2000	535.3
2001	528.8
2002	373.8

¹ Unpublished data from Measles & Rubella, Annual Report 2012, page 11 (April 2013).

ESTIMATED NUMBER OF GLOBAL MEASLES DEATHS, 2000–2010—Continued
[In thousands]

	Number
2003	484.3
2004	331.4
2005	384.8
2006	227.7
2007	130.1
2008	137.5
2009	177.9
2010	139.3

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$1 billion and provided technical support in more than 80 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2011, an estimated 10 million measles deaths were averted as a result of these accelerated measles control activities at a donor cost of less than \$200/death averted, making measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. The Initiative and its partners have supported the distribution of more than 245 million doses of vitamin A, 113 million doses of de-worming medicine, 41 million insecticide-treated bed nets, and 137 million doses of polio vaccine. Doses of oral polio vaccines are frequently distributed during measles campaigns in polio endemic and high risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

The extraordinary reduction in global measles deaths contributed nearly 25 percent of the progress to date toward Millennium Development Goal #4 (reducing under-five child mortality). However, large outbreaks in several African, European and Asian countries in 2011 and 2012 have put the 2015 measles elimination goals at risk. These outbreaks highlight the fragility of the last decade’s progress. If mass immunization campaigns are not continued, measles deaths will increase rapidly with more than half a million deaths estimated for 2013 alone.

To achieve the 2015 goal and avoid a resurgence of measles the following actions are required:

- Fully implementing activities, both campaigns and strengthening routine measles coverage, in India since it is the greatest contributor to the global burden of measles.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90 percent of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
- Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from the GAVI Alliance.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. The Measles & Rubella Initiative faces a funding shortfall of an estimated U.S. \$171 million for 2013–2015. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles elimination activities makes increased political commitment and coun-

try ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. children are also being protected from the diseases. Measles can cause severe complications and death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year, particularly from Europe. The costs of these cases and outbreaks are substantial, both in terms of the costs to public health departments and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between \$100,000 and \$200,000 to control. The U.S. had 222 measles cases in 2011, the highest in 15 years and Canada experienced a large outbreak of over 800 cases.

The Role of CDC in Global Measles Mortality Reduction

Since fiscal year 2001 and until 2013, Congress has provided between \$43.6 and \$49.3 million annually in funding to CDC for global measles control activities. These funds were used toward the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 80 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Congress—was essential in helping achieve the sharp reduction in measles deaths in just eleven years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2011 and fiscal year 2012, Congress appropriated approximately \$49 million each year to fund CDC for global measles control activities. This amount represents a \$2.7 million decrease from 2010. The American Red Cross and the United Nations Foundation respectfully request a return to fiscal year 2010 funding levels (\$52 million) for fiscal year 2014 for CDC's measles and rubella control activities to protect the investment of the last decade, and prevent a global resurgence of measles and a loss of progress toward Millennium Development Goal #4.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates the opportunity to comment on fiscal year 2014 appropriations for the Title VIII Nursing Workforce Development Programs and Nurse-Managed Health Clinics. Founded in 1896, ANA is the

only full-service professional association representing the interests of the Nation's 3.2 million registered nurses (RNs) and advanced practice registered nurses (APRNs-including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists) through its State nurses associations, and organizational affiliates. The ANA advances the nursing profession by fostering high standards of nursing practice, promoting the rights of nurses in the workplace, and projecting a positive and realistic view of nursing.

As the largest single group of clinical health care professionals within the health system, licensed registered nurses are educated and practice within a holistic framework that views the individual, family and community as an interconnected system that can keep us well and help us heal. As the Nation works towards restructuring the healthcare system by focusing on expanding access, decreasing cost, and improving quality; a significant investment must be made in strengthening the nursing workforce.

We are grateful to the subcommittee for your past commitment to Title VIII funding, and we understand the immense fiscal pressures the subcommittee is facing. However, ANA respectfully requests your support of \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014. Additionally, we respectfully request \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2014. While we recognize the reality of the sequester and the need to continue to cut the Federal deficit, we also firmly believe this request is necessary given the demand for nursing services is steadily on the rise.

DEMAND FOR NURSES CONTINUES TO GROW

A sufficient supply of nurses is critical in providing our Nation's population with quality health care now and into the future. Registered Nurses (RNs) and Advanced Practice Registered Nurses (APRNs) are the backbone of hospitals, community clinics, school health programs, home health and long-term care programs, and serve patients in many other roles and settings. The Bureau of Labor Statistics' (BLS) Employment Projections for 2010–2020 state the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26 percent.

Contrary to the good news that there are a growing number of nurses, the current nurse workforce is aging. According to the 2008 National Sample Survey of Registered Nurses, over one million of the Nation's 2.6 million practicing RNs are over the age of 50. Within this population, more than 275,000 nurses are over the age of 60. As the economy continues to rebound, many of these nurses will seek retirement, leaving behind a significant deficit in the number of experienced nurses in the workforce. According to Douglas Staiger, author of a New England Journal of Medicine study, the nursing shortage will "re-emerge" from 2010 and 2015 as 118,000 nurses will stop working full time as the economy grows.

Furthermore, as of January 1, 2011 Baby Boomers began turning 65 at the rate of 10,000 a day. With this aging population, the healthcare workforce will need to grow as there is an increase in demand for nursing care in traditional acute care settings as well as the expansion of non-hospital settings such as home care and long-term care.

The BLS projections explain a need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020. A shortage of this magnitude would be twice as large as any shortage experienced by this country since the 1960s. Cuts to Title VIII funding would be detrimental to the health care system and the patients we serve.

TITLE VIII: NURSING WORKFORCE DEVELOPMENT PROGRAMS

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.), includes programs such as Nursing Loan Repayment Program and Scholarships Program, (Sec. 846, Title VIII, PHSA); Advanced Nursing Education (ANE) Grants; (Sec. 811), Advanced Education Nursing Traineeships, (AENT); Nurse Anesthetist Traineeships (NAT); Comprehensive Geriatric Education Grants, (Sec. 855, Title VIII, PHSA); Nurse Faculty Loan Program, (Sec. 846 A, Title VIII, PHSA); and Nursing Workforce Diversity Grants, (Sec. 821). These programs support the supply and distribution of qualified nurses to meet our Nation's healthcare needs.

Without support for Title VIII funding and nursing education; there will be a shortage of nurse educators. With a shortage of nurse educators, schools will have to turn away nursing students. With less financial assistance to deserving nursing students; there will be fewer nursing students. With fewer nursing students, there

will be fewer nurses. As noted above, the nursing shortage will have a detrimental impact on the entire health care system.

Numerous studies have shown that nursing shortages contribute to medical errors, poor patient outcomes, and increased mortality rates. A study published in the March 17, 2011 issue of the *New England Journal of Medicine* shows that inadequate staffing is tied to higher patient mortality rates. The study supports findings of previous studies and finds that higher than typical rates of patient admissions, discharges, and transfers during a shift were associated with increased mortality—an indication of the important time and attention needed by RNs to ensure effective coordination of care for patients at critical transition periods.

Over the last 48 years, Title VIII programs have provided the largest source of Federal funding for nursing education; offering financial support for nursing education programs, individual students, and nurse educators. These programs bolster nursing education at all levels, from entry-level preparation through graduate study and in many areas including rural and medically underserved communities.

The American Association of Colleges of Nursing's (AACN) Title VIII Student Recipient Survey gathers information about Title VIII dollars and its impact on nursing students. The 2011–2012 survey, which included responses from over 1,600 students, stated that Title VIII programs played a critical role in funding their nursing education. The survey showed that 68 percent of the students receiving Title VIII funding are attending school full-time. Between fiscal year 2005 and 2010 alone, the Title VIII programs supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities.

However, current funding levels are falling short of the growing need. In fiscal year 2008 (most recent year statistics are available), the Health Resources and Services Administration (HRSA) was forced to turn away 92.8 percent of the eligible applicants for the Nurse Education Loan Repayment Program (NELRP), and 53 percent of the eligible applicants for the Nursing Scholarship program due to a lack of adequate funding. These programs are used to direct RNs into areas with the greatest need—including community health centers, departments of public health, and disproportionate share hospitals. Additionally according to the AACN Title VIII Student Recipient Survey, a record 58,327 qualified applicants were turned away due to insufficient clinical teaching sites, a lack of faculty, limited classroom space, insufficient preceptors and budget cuts.

Monies you appropriate for these programs help move nurses into the workforce without delay. Your investment in programs, and the nurses that participate, is returned by more students entering into the profession and serving in rural and underserved areas; by nurses continuing with their education and studying to be nurse practitioners, thereby addressing our Nation's growing need for primary care providers; or by going on to become a nurse faculty member and teaching the next generation of nurses.

While ANA appreciates the continued support of this subcommittee, we are concerned that Title VIII funding levels have not been sufficient to address the growing nursing shortage. Registered Nurses (RNs) and Advanced Practice Nurses (APRNs) are key providers whose care is linked directly to the availability, cost, and quality of healthcare services. For these reasons and many more, we again respectfully request you appropriate \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014.

NURSE-MANAGED HEALTH CLINICS

A health care system must value primary care and prevention to achieve an improved health status of individuals, families and the community. Nurses are strong supporters of community and home-based models of care. We believe that the foundation for a wellness-based health care system is built in these settings and reduces the amount of both financial expenditures and human suffering. ANA supports the renewed focus on new and existing community-based programs such as Nurse Managed Health Clinics (NMHCs).

Currently, there are more than 200 Nurse Managed Health Clinics (NMHCs) in the United States which have provided care to over 2 million patients annually. ANA believes that Nurse Managed Health Clinics (NMHCs) are an efficient, cost-effective way to deliver primary health care services. NMHCs are effective in disease prevention and early detection, management of chronic conditions, treatment of acute illnesses, health promotion, and more. These clinics are also used as clinical sites for nursing education.

We respectfully request the committee provide \$20 million for the Nurse-Managed Health Clinics authorized under Title VIII of the Public Health Service Act in fiscal year 2014.

Thank you for your time and your attention to this matter.

PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) is the largest scientific and professional organization representing psychology in the U.S.: Membership includes more than 137,000 researchers, educators, clinicians, consultants and students. Through its divisions in 54 subfields of psychology and affiliations with 60 State, territorial and Canadian provincial associations, APA works to advance the creation, communication and application of psychological knowledge to benefit society and improve people's lives.

APA is very concerned that deficit reduction efforts to date—both actual and those under consideration—have relied almost exclusively on cuts to public health, health research, and other discretionary programs. Public health and health research programs have experienced three consecutive years of cuts. Under sequestration, these cuts will be even deeper. We urge this Committee to consider the critical role of the Public Health Service agencies in our Nation's security, infrastructure and economic growth when making funding decisions.

As a member of the Centers for Disease Control and Prevention (CDC) Coalition, APA supports at least \$7.8 billion for CDC core programs in fiscal year 2014. CDC programs play a key role in protecting Americans from public health threats and emergencies, and in reducing healthcare costs and strengthening the Nation's health system. In addition to the significant overall funding cuts that the CDC has seen in recent years, funding for the agency has increasingly relied heavily on the Prevention and Public Health Fund and other fund transfers, so that the agency has seen deep cuts to its budget authority. The Prevention and Public Health Fund was intended to supplement and not supplant the base funding of our public health agencies and programs. APA urges the Committee to restore CDC's budget authority.

As a member of the Friends of the National Center for Health Statistics (NCHS), APA recommends \$181.5 million for the center in fiscal year 2014, consistent with the President's request. The data collected by NCHS on chronic disease prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death, and rates of insurance, to name a few, are essential to the Nation's statistical and public health infrastructure. The Committee's leadership in securing stable funding has helped NCHS rebuild after years of underinvestment and stabilize the collection of essential health data.

APA applauds the NCHS's progress including questions related to sexual orientation in the National Health Interview Survey (NHIS), and urges that other Federal surveys to follow suit. Still, there is slower progress toward inclusion of gender identity questions. APA urges the Committee to ensure that milestones established in the July, 2011 national data progression plan are met.

APA is pleased that the Committee has continued to designate specific funding for the CDC's Prevention Research Centers (PRC) program, and urges the Committee to restore funding for the program to at least \$28 million in fiscal year 2014, consistent with fiscal year 2011 funding levels. The PRC network of community, academic, and public health partners makes significant research contributions that are essential to the focus on prevention that is critically needed to improve health in America.

APA asks the Committee to encourage the National Center on Injury Prevention and Control to increase research on the psychological impact of intimate partner and sexual violence in order to increase and improve evidence based interventions to support the recovery of women from the trauma of violence.

Finally, APA strongly supports the President's request for \$10 million for gun violence prevention research and for \$20 million for expansion of the CDC's National Violent Death Reporting System. The freeze on Federal funding for gun violence research has significantly hampered psychological scientists' ability to systematically assess risks and to determine the effectiveness of various preventive measures. A new IOM committee on priorities for a public health research agenda to reduce the threat of firearm-related violence recently hosted a workshop where scientists from a range of fields, including psychology, presented on very promising topics for future and continued research, necessary for closing the gaps in knowledge about this devastating problem that faces our Nation and for determining effective solutions.

APA supports at least \$32 billion for the National Institutes of Health in fiscal year 2014. This represents the minimum investment necessary to avoid further loss of promising research, and at the same time allows the NIH's budget to keep pace with biomedical inflation. NIH drives scientific innovation and develops new and better diagnostics, improved prevention strategies, and more effective treatments. NIH supports critical behavioral research on aging, memory, learning, child development, behavior change and maintenance, and prevention and treatment of many chronic and acute conditions. Just a few highlights:

- NIMH-supported research has shown that biomedical approaches to HIV prevention are most effective when they are combined with behavioral approaches. Behavioral research is needed more than ever to bolster medication adherence and treatment uptake, to document real-world decision-making processes associated with biomedical interventions, and to better understand potential unintended and/or undesired consequences of biomedical interventions.
- NICHD-supported research is examining the critical impact of stress in altering a child's developmental trajectories. Investment in additional longitudinal research is needed to understand the long-term impact of stress on mental health outcomes, cognitive, emotional and social development, including self-control, inhibitory response, executive functioning, attention, memory and learning skills and how those variables impact later adolescent health behaviors, childhood obesity and academic achievement.
- NIA-supported research is focusing on the feasibility of reversing childhood disadvantage in later life.
- NIDDK-supported research is exploring ways in which basic behavioral research can be applied to the problem of obesity.
- APA commends NIH for addressing the need for a more diverse biomedical and behavioral research workforce and is encouraged that NIH is examining the factors contributing to this disparity in funding success, including the role of bias in the peer review process, the process by which funding decisions are made, and training/mentoring and support programs for under-represented investigators across the pipeline and at critical career decision points. APA encourages the Committee to continue to press NIH to improve common data collected and measured across the biomedical and behavioral workforce, including those programs that track underrepresented students and investigators. Such efforts will provide the much needed information and direction regarding what programs and initiatives are most successful at enhancing the diversity of the scientific workforce.

Turning to the Center for Mental Health Services, APA is concerned that while minorities represent 30 percent of the population and are projected to increase to 40 percent by 2025, only 23 percent of recent doctorates in psychology, social work and nursing were awarded to minorities. We encourage the Committee to increase funding for the Minority Fellowship Program by \$4.4 million as requested in the President's fiscal year 2014 budget proposal. The increase reflects the need to continually grow the pool of culturally competent mental health professionals.

APA strongly supports the work of SAMHSA's National Child Traumatic Stress Network (NCTSN) program and recommends increased support for the Network and its efforts on behalf of the recovery of children, families, and communities affected by physical and sexual abuse, school and community violence, natural disasters, sudden death of a loved one, the impact of war on military families, and other sources of trauma.

Given that approximately 20–25 percent of older adults have a mental or behavioral health problem, and older white males (age 85 and over) currently have the highest rates of suicide of any group in the U.S. APA supports an expanded effort to address the mental and behavioral health needs of older adults including implementation of the mental and behavioral health provisions in the Older Americans Act Amendments of 2006, grants to States for the delivery of mental health screening, and treatment services for older individuals and programs to increase public awareness and reduce the stigma associated with mental disorders in older individuals.

APA also recommends continued support of the HHS's Lifespan Respite Program. Respite care can provide family caregivers with relief necessary to maintain their own health, bolster family stability and well-being, and avoid or delay more costly nursing home or foster care placements.

In an effort to efficiently and effectively address the mental health issues facing our Nation, APA strongly urges the Committee to invest in programs already established and currently serving the Nation's needs to increase access to mental and behavioral health services and to increase the number of psychologists trained to provide those documented and needed mental and behavioral health services to those

who need it throughout the country. APA urges Congress to fund the Health Resources and Services Administration's Graduate Psychology Education program (GPE) at \$4.5 million. This level represents a restoration to previously funded level for fiscal year 2003–2005 and would allow for 35–40 grants nationwide with over 900 eligible universities and hospitals. According to the President's Budget for fiscal year 2010–2011 in that year alone the GPE Program enabled the addition of 620 doctoral level trainees to be trained through an interdisciplinary approach to provide mental and behavioral health services to approximately 46,000 underserved children, older adults, chronically ill persons, and victims of abuse and trauma including veterans and their families.

In addition, APA urges support of the programs funded under the Garrett Lee Smith Memorial Act at least at current appropriated levels. The suicide prevention programs authorized under the GLSMA and administered by the Substance Abuse and Mental Health Services Administration—State/Tribal, Campus, and the Technical Assistance Center—provide critical services to our youth population. Mental disorders account for nearly one-half of the disease burden for young adults in the United States, according to the *Journal of Adolescent Health's* January 2010 article, *Mental Health Problems and Help-Seeking Behavior among College Students*. Further, suicide is the second-leading cause of death for adolescents and young adults between the ages of 10 and 24 and results in 4,850 lives lost each year, according to the Centers for Disease Control and Prevention. Any Federal efforts to provide needed services to this population should be supported by investing in the GLSMA programs.

APA appreciates the Committee's efforts to support these programs which benefit all Americans.

PREPARED STATEMENT OF THE AMERICAN PUBLIC HEALTH ASSOCIATION

The American Public Health Association is the collective voice advocating for the public's health. As a diverse community of public health professionals, we've championed the health of all people and communities around the world for more than 140 years. We are pleased to submit our views regarding the fiscal year 2014 budgets of the Centers for Disease Control and Prevention and the Health Resources and Services Administration. We urge you to take our recommendations into consideration as you move forward with writing the fiscal year 2014 Labor-HHS-Education Appropriations bill.

CENTERS FOR DISEASE CONTROL AND PREVENTION

APHA believes that that Congress should support CDC as an agency—not just the individual programs that it funds. Given the challenges and burdens of chronic disease, the ongoing threat of an influenza pandemic, constant public health emergencies, new and reemerging infectious diseases and our many unmet public health needs and missed prevention opportunities—we urge a funding level of \$7.8 billion for CDC's programs in fiscal year 2014. Unfortunately, the President's fiscal year 2014 budget request for CDC represents a nearly \$277 million reduction when compared with fiscal year 2012. These proposed cuts come on top of the \$577 million reduction to CDC in fiscal year 2013 due to the sequester and reduction in Prevention and Public Health Fund resources. After these cuts, CDC's budget authority is now lower than 2003 levels.

At the same time State and local health departments are operating on tight budgets and with a smaller workforce. Since 2008, more than 46,000 State and local public health jobs have been lost. These cuts are simply not sustainable and will reduce the ability of CDC and its State and local grantees to investigate and respond to public health emergencies as well as food borne and infectious disease outbreaks.

By translating research findings into effective intervention efforts, CDC is a critical source of funding for many of our State and local programs that aim to improve the health of communities. Perhaps more importantly, Federal funding through CDC provides the foundation for our State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC also serves as the command center for our Nation's public health defense system against emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic and the many other natural and man-made threats that exist in the modern world, CDC has become the Nation's—and the world's—expert resource and response center, coordinating communications and action and serving as the laboratory reference center. States and communities rely on CDC for accurate information and direction in a crisis or outbreak.

CDC serves as the lead agency for bioterrorism and other public health emergency preparedness and response programs and must receive sustained support for its preparedness programs in order for our Nation to meet future challenges. Given the challenges of terrorism and disaster preparedness, and our many unmet public health needs and missed prevention opportunities we urge you to provide adequate funding for State and local capacity grants. Unfortunately, this is not a threat that is going away.

CDC plays a significant role in addressing chronic diseases such as heart disease, stroke, cancer, diabetes and arthritis that continue to be the leading causes of death and disability in the United States. These diseases, many of which are preventable, are also among the most costly to our health system. CDC's National Center for Chronic Disease Prevention and Health Promotion provides critical funding for State programs to prevent chronic disease, conducts surveillance to collect data on disease prevalence and monitor intervention efforts and translates scientific findings into public health practice in our communities.

CDC's National Center for Environmental Health is essential to protecting and ensuring the health and well being of the American public by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. We encourage the subcommittee to provide adequate funding for NCEH programs which has been significantly cut in recent years.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA operates programs in every State and U.S. territory and is a national leader in providing health services for individuals and families. Roughly 55 million Americans are currently uninsured and more than 60 million live in rural communities where primary health care services are scarce—the agency serves as a health safety net for the medically underserved and works to improve their health. To respond to these challenges, APHA believes that the agency will require funding of \$7.0 billion for discretionary HRSA programs in fiscal year 2014.

The recommended funding level takes into account the need to reduce the Nation's deficit while prioritizing the immediate and long-term health needs of Americans. We are deeply concerned with the failure to avert the sequester that will cut over \$311 million from HRSA's fiscal year 2013 discretionary funding. These cuts come on top of the 17 percent or more than \$1.2 billion reduction to HRSA's budget authority since fiscal year 2010. Unfortunately, the President's fiscal year 2014 budget request for HRSA proposes a more than \$193 million reduction when compared with fiscal year 2012. HRSA's ability to prevent sickness, keep people healthy and treat illness or injury for millions of Americans will be severely compromised, by across-the-board cuts if the sequester is not reversed and the cuts restored. Our recommended funding level is necessary to ensure HRSA is able to implement essential public health programs, including training for public health and health care professionals, providing primary care services through health centers, improving access to care for rural communities, supporting maternal and child health care programs and providing health care to people living with HIV/AIDS. In addition to delivering much needed services, the programs provide an important source of local employment and economic growth in many low-income communities.

Our recommendation is based on the need to continue improving the health of Americans by supporting critical HRSA programs, including:

- Health Professions* programs support the education and training of primary care physicians, nurses, dentists, optometrists, physician assistants, mental and behavioral health professionals and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the Nation's growing, aging and increasingly diverse population.
- Primary Care* programs support nearly 8,900 community health centers and clinics in every State and U.S. territory, improving access to care for more than 20 million patients in geographically isolated and economically distressed communities. Close to half of these health centers serve rural populations. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
- Maternal and Child Health* programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others support a myriad of initiatives designed to promote optimal health, reduce disparities, combat infant mortality,

prevent chronic conditions and improve access to quality health care for more than 40 million women and children, including children with special health care needs.

- HIV/AIDS* programs provide assistance to States and communities most severely affected by HIV/AIDS. The programs deliver comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for roughly half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
- Family Planning* Title X services ensure access to a broad range of reproductive, sexual and related preventive healthcare for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. This program helps improve maternal and child health outcomes and promotes healthy families.
- Rural Health* programs improve access to care for people living in rural areas where there is a shortage of health care services. These programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.

PREVENTION AND PUBLIC HEALTH FUND

We are deeply disappointed with the diversion of more than \$450 million from the Prevention and Public Health Fund in fiscal year 2013 to pay for implementing the health exchanges through the Affordable Care Act. Between the reduction due to sequestration (–\$51 million) and the net diversion of resources for implementation of health exchanges (–\$332 million), programs currently supported by the fund are faced with a more than 38 percent cut from fiscal year 2012. While the HHS Secretary Sebelius was able to transfer some additional discretionary funding to blunt some of the cuts to agencies such as CDC, we urge you to oppose any future efforts to divert this funding and to instead appropriate adequate funding for ACA implementation in fiscal year 2014. We are pleased that the President's fiscal year 2014 budget proposal restores the use of the fund to its original intent. We urge the Senate Appropriations Committee to work with the administration to ensure this funding goes toward supporting State, local, tribal and community-based activities in all 50 States for community prevention, tobacco use prevention, obesity prevention and fitness, and clinical prevention.

CONCLUSION

In closing, we emphasize that the public health system requires stronger financial investments at every stage. This funding makes up only a fraction of Federal spending and continued cuts to public health and prevention programs will not balance our budget, it will only lead to increased costs to our health care system. Successes in biomedical research must be translated into tangible prevention opportunities, screening programs, lifestyle and behavior changes and other population-based interventions that are effective and available for everyone. Without a robust and sustained investment in our public health agencies, we will fail to meet the mounting health challenges facing our Nation.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) is pleased to submit the following statement on the fiscal year 2014 appropriation for the Centers for Disease Control and Prevention (CDC). The ASM is the largest single life science organization in the world with approximately 37,000 members.

The CDC is the lead Federal agency to prevent disease, injury, and disability and it must be adequately resourced for known and new public health threats. CDC partners with State and local health departments and global organizations and CDC medical personnel, scientists and other public health professionals respond to public health events 24/7 wherever needed. CDC experts react quickly to events here and abroad, ranging from foodborne illness outbreaks or previously unknown infectious pathogens, to the health crises following earthquakes or typhoons.

The ASM is very concerned that budgetary cuts are seriously eroding CDC's capabilities in key areas like surveillance, laboratory diagnosis, and control and prevention strategies. The budget constraints now in effect will prove deleterious to our

Nation's public health system. Sequestration mandated cuts will certainly weaken or even eliminate important CDC activities. CDC officials have already announced probable decreases in grant award amounts and in numbers of new awards. Sequestration is expected to cut CDC support to States by more than \$200 million, which will unquestionably affect responses to disease outbreaks and other urgent public health problems.

Recent outbreak investigations point to the CDC's unique and multifaceted capabilities that are at risk under budget shortages. Last year, CDC personnel tracked the fungal meningitis linked to contaminated steroid injections, with over 700 cases and almost 50 deaths across 20 States. CDC's epidemiologists and laboratories investigated hantavirus infection among visitors to Yosemite National Park, bacterial infections in pediatric oncology patients in Colorado, the unprecedented outbreak of West Nile encephalitis in the Dallas/Fort Worth area. CDC also supported international efforts against infectious diseases, investigating cholera in Sierra Leone, anthrax in the Republic of Georgia, Marburg hemorrhagic fever in Uganda, and other outbreaks elsewhere. CDC funding is critical to building and maintaining the expertise necessary to sustain CDC's rapid responses to public health threats in the U.S. and worldwide.

As the Nation's public health agency, CDC continually faces challenges like microbial agents of infectious disease and other illnesses. One in six Americans gets sick each year from eating contaminated food; more than 1,000 foodborne outbreaks are reported to CDC officials annually. The CDC estimates that, each year in the United States, there are nearly 20 million new sexually transmitted diseases (STD) infections incurring lifetime medical costs of \$15.6 billion. Despite progress in treating HIV infection, significant challenges remain (e.g., in 2010, an estimated 12,200 new infections in people in the U.S. aged 13–24; in 2011, 2.5 million people newly infected worldwide). Nearly 900,000 children in other countries still die each year from vaccine preventable diseases like rotavirus, hepatitis B, pneumococcal pneumonia, and meningitis. The U.S. has also witnessed a recent upsurge in vaccine-preventable diseases, with over 42,000 cases of pertussis (whooping cough) reported in 2012 alone and declared epidemics in several States. Globalization has meant fewer barriers to the spread of infectious diseases, making CDC's multi-talented programs even more essential. Human migration contributes considerably to the spread of disease: Each year, about 214 million people move across national borders, three quarters billion within their own countries, and nearly 3 billion travel by plane.

CDC Funding Provides Rapid Response, Surveillance

CDC has more than 15,000 employees and has personnel deployed to over 50 countries, trained to protect through health promotion, prevention of disease and disability, and preparedness. Such widespread, diverse expertise gives CDC its agility to detect and define an expansive array of threats and to respond quickly. The 2012–2017 strategic plan of CDC's National Center for Emerging and Zoonotic Infectious Diseases (NCEZID) underscores the complexities involved—one overall strategy, intended to “strengthen public health fundamentals,” directs CDC personnel to “advance and increase effectiveness of infectious disease laboratory science, surveillance, epidemiology, information technology, communications, and strategic partnerships.” The CDC budget directly support extensive surveillance, science based epidemiology, and other tools effective in combating disease.

CDC investigations vary from behind the scenes lab support for localized incidents to frontline responses in highly visible outbreaks. An example is CDC's current collaboration with the World Health Organization (WHO) to better understand a previously unknown respiratory virus, related to the SARS virus that emerged in China in 2002 and rapidly infected 8,000 worldwide. The new coronavirus, thus far called NCoV for novel coronavirus, causes severe lower respiratory disease. As of March 7, there were only 14 confirmed cases reported to WHO, with eight deaths, all among patients with ties to the Middle East, and thus far no cases have been identified in the United States. But CDC and other health organizations that have already faced fast moving outbreaks like SARS are concerned by similar evidence of human-to-human transmission and spread of the virus to other countries, especially given the conflicts and volatility currently engulfing the Middle East. CDC laboratories also are conducting tests on patient specimens to isolate the new virus, as public health officials prepare to engage yet another communicable disease.

CDC regularly applies its scientific expertise and laboratory capabilities to investigate outbreaks both large and limited in scope, including these recent examples: —CDC investigated more than 300 cases of swine-origin variant influenza virus that occurred last summer and fall across 9 midwestern and mid-Atlantic States. Most cases were in children who attended or exhibited swine at agricultural fairs, and a number of hospitalizations and one death occurred. This virus

has acquired genetic material from the 2009 pandemic H1N1 virus, raising concerns about its pandemic potential. CDC and States have been working with 4-H clubs, USDA, and State agriculture agencies to address this emerging public health concern and reduce the risk for the upcoming fair season.

- CDC is collaborating with the U.S. Department of Agriculture’s Animal and Plant Health Inspection Service and State health departments to follow an outbreak of human *Salmonella* typhimurium infections linked to contact with pet hedgehogs. The outbreak strain had been rare, with only one to two cases reported via PulseNet (the national network for foodborne disease surveillance) annually since 2002. Since 2011, an increasing number of cases have been detected, with 14 in 2011, 18 in 2012, and two thus far in 2013.
- In August, CDC investigators and the FDA linked a multi-State outbreak of salmonellosis to contaminated cantaloupes from an individual farm, using pulsed field gel electrophoresis analysis of patient samples. There are over 2,700 serotypes of foodborne *Salmonella* bacteria, and advanced diagnostic tests used by CDC are essential in accurately pinpointing sources.
- In January, CDC summarized its foodborne surveillance for 2009–2010: 1,527 foodborne disease outbreaks reported, involving 29,444 cases of illness. Among the 790 events with a single confirmed pathogen, 42 percent were caused by norovirus, 30 percent by *Salmonella*.

CDC must also address the alarming rise of drug resistant pathogens, including Carbapenem Resistant Enterobacteriaceae (CRE). Multiple CDC networks, with input from State health departments, have detected increased cases over the past decade, warning of a potential “nightmare” scenario. CDC officials just released strongly worded reports on the pathogen’s “triple threat”: (1) resistant to all, or nearly all, available antibiotics; (2) causes a high mortality rate (40–50 percent); and (3) can transfer antibiotic resistance to certain other bacteria, even those normally benign. This is yet another example of the continuing threat of health care associated infections (HAIs).

Surveillance networks hosted by CDC collect data on a long list of diseases, using powerful computing and two way communication with thousands of public health partners. These help guide CDC strategy, providing another weapon against both emerging threats, like chikungunya virus or multidrug resistant tuberculosis, and longtime problems like foodborne illnesses. Last year, for instance, CDC surveillance identified a resurgence of WNV infections: By mid-December, there had been nearly 5,390 U.S. cases reported from 48 States, the highest number since 2003. Since 1999, when WNV was first identified in the United States, CDC has tabulated more than 30,000 cases. With transfusion associated cases first reported in 2002, CDC and its partners implemented WNV screening of the U.S. blood supply in 2003, preventing an estimated 3,000 to 9,000 transfusion related infections.

CDC Funding Protects, Promotes Public Health

Using surveillance data, public education, and tools like vaccines, CDC strives to prevent illness and injury, being proactive well beyond reacting to disease outbreaks. To illustrate, although CRE is still limited in the United States, it is typically acquired within healthcare settings. This has prompted CDC to develop a CRE action plan, part of its ongoing education campaigns to both minimize drug resistance among pathogens and prevent costly healthcare associated infections (HAIs). In its latest progress report (February 2013), CDC listed successes against some types of HAIs using stringent infection control measures; for example, a 41 percent reduction in central line associated bloodstream infections since 2008. These CDC efforts embody the obvious: that prevention quite literally is more cost effective than finding a cure.

There are few public health measures as historically effective as immunization against communicable diseases. Both in the United States and elsewhere, CDC has been a major contributor, of personnel, vaccines, expert support systems, to national and global immunization campaigns like those against smallpox and polio. As of 2010, 85 percent of children aged 12–23 months were immunized against measles worldwide. Over the previous decade, measles deaths had been cut by 74 percent. In this country, CDC vigorously promotes vaccination against childhood infectious diseases, influenza, hepatitis, and more. It also evaluates new candidate vaccines through collaborations with medical schools and other Federal agencies. Yet last year’s outbreak of whooping cough, a vaccine preventable disease, is a reminder that U.S. vaccination coverage is incomplete and that CDC education efforts must continue.

The ASM strongly urges that Congress increase the CDC budget in fiscal year 2013 and fiscal year 2014 and fund the CDC at the highest possible level.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) is pleased to submit the following statement on the fiscal year 2014 appropriation for the National Institutes of Health (NIH). The ASM is the largest single life science organization in the world with more than 37,000 members.

The NIH supports research programs essential to public health and to stimulating valuable economic sectors in health care and biomedical sciences, and creating our future scientific workforce. The current fiscal impasse is alarming to the biomedical research community. NIH appropriations already had fallen short in recent years, with the Agency losing one-fifth of its purchasing power over the past decade. The budget sequestration now in effect would further cut NIH funding by over 5 percent in the current fiscal year, which actually would equal nearly 9 percent over the remaining fiscal year 2013 period.

The ASM is very concerned by the probable fallout from this additional approximately \$1.6 billion decrease in NIH's fiscal year 2013 funding, particularly when biomedical research should receive more, not less, Federal support. NIH recently informed the scientific community that all grant awards currently being funded likely would receive less than their full fiscal year 2013 commitment levels. Under sequestration, the Agency also will distribute fewer new awards. The most recent success rate of grant applications was already at a low 18 percent compared with 30 percent in 2003. In February, analysis by United for Medical Research (UMR) projected that sequestration of NIH funding could force the loss of 20,500 U.S. jobs and \$3 billion in economic output. Sequestration decreases foreshadow the already grim scenario of an estimated \$900 billion in NIH spending cuts over the next 10 years mandated under the Budget Control Act.

NIH funding jeopardizes the Nation's competitive edge in biomedicine and thus our economic success in the innovation dependent global marketplace. Budget cuts also will have a chilling effect on whether young Americans choose research careers, if those careers appear to lack professional and financial stability. It is generally agreed that the United States must attract and inspire, not discourage, the next generation of scientists. We urge Congress to also recognize that inadequate NIH funding would fail a national public health system faced with rising healthcare costs, as well as an aging and increasingly diverse population. In 2011, national health spending reached an estimated \$2.7 trillion (17.9 percent of the GDP), a startling argument for those effective disease treatment and prevention approaches discovered through NIH funding.

The ASM strongly urges Congress to add additional funding for the NIH in fiscal year 2013 and fiscal year 2014 and fund the NIH at the highest possible level of funding.

NIH Funding of Biomedical Research is Essential to the Fight against Infectious Diseases

Biomedical advances extend life expectancy and steadily improve our quality of life. Examples include HIV/AIDS studies transforming a fatal disease into a chronic condition through treatment, and the vaccine development responsible for dramatic global declines in diphtheria, polio, yellow fever, tetanus, and smallpox. Each year, three NIAID supported vaccines are now saving numerous children worldwide: pneumococcal vaccine, 826,000; Haemophilus influenzae type b vaccine, 386,000; and rotavirus vaccine, 435,000.

Despite lower mortality from communicable causes, infectious diseases persist as significant threats to public health. Detecting, preventing, and treating infectious diseases is a critical part of NIH's portfolio. In allocating resources, it is important to remember that NIH is the Nation's primary Federal supporter of basic, clinical, and translational research in medicine, generating diagnostics, therapeutics, prevention strategies, and surveillance tools that help lift the burden of infectious disease.

Health agencies in the United States periodically confront infectious diseases variously classified as newly emerging, reemerging/resurging, or deliberately emerging (bioterrorism), as well as pathogens increasingly resistant to drug therapy. In recent years, these so called emerging infectious diseases (EID) have included those caused by hantavirus, HIV, and highly virulent strains of E. coli and influenza viruses; rising numbers of dengue, listeriosis, and West Nile; and drug resistant forms of Staphylococcus aureus. In 2012 alone, emerging examples included a novel disease causing coronavirus initially reported in the Middle East and a variant influenza virus (H3N2v) that spread from swine to people in U.S. farm communities. The media report this month (March) of a man infected with a deadly form of the tuberculosis pathogen, one considered to be "extensively drug-resistant" (XDR TB), is just the most recent reminder that we cannot afford to fall behind in our understanding

of, and science based responses to, microbial pathogens and their host interactions. U.S. health officials found his TB strain to be resistant to at least eight of the available standard drugs. Before being stopped at the U.S.-Mexico border and placed in medical isolation, he had traveled through 13 countries over 3 months. XDR poses a major threat due to its frightening drug resistance.

Scientists funded by the NIAID consistently achieve advances against HIV/AIDS, malaria, tuberculosis, influenza, and other diseases significant to our health and economy. To illustrate their importance, NIAID supported these examples from the past year:

- Genetic changes in the salivary glands of mosquitoes infected with dengue virus might increase virus transmission, elucidating viral biology that must be understood to develop countermeasures. There currently is no vaccine or drug treatment for dengue, which globally infects about 50 million to 100 million each year and has been reported in parts of the United States.
- Discovery of a toxin transport system in *S. aureus* suggests a new approach to drugs against a pathogen notorious for its ability to resist traditional antibiotics. Methicillin resistant staph (MRSA) is a leading cause of U.S. hospital acquired infections, causing an estimated 18,000 deaths in 2005. In other research, genome sequencing of multiple strains of vancomycin resistant *S. aureus* gives scientific insight into pathogens resistant to an antibiotic of last resort.
- Universal flu vaccines against a wide range of virus strains are moving closer to reality with results from studies like those of human immune cells producing broadly neutralizing antibodies against flu viruses and those showing that a prime boost vaccine regimen can elicit “universal” antibody production. Several clinical trials of first generation universal vaccines are either under way or planned at NIAID’s Vaccine Research Center.
- Clinical trials demonstrated the most effective antiretroviral drug regimens to prevent HIV infection (pre-exposure prophylaxis, or PrEP); other research helped shape antiretroviral treatment for HIV infected individuals. Last August, NIAID awarded \$7.8 million in first year funding to universities and medical centers for basic research to identify new approaches in HIV vaccine design, part of a much larger HIV vaccine discovery effort.

The NIGMS has funded basic research on the structure and function of HIV, in search of new treatments, for more than 25 years. It is a partner with the National Science Foundation, the U.S. Department of Agriculture and others in the Ecology and Evolution of Infectious Diseases (EEID) program, contributing expertise in basic research. Last year, NIGMS supported scientists developed a new improved CH-activation technique to add molecules to existing compounds, making it easier to tailor make new drugs; others reported on how iron uptake plays a role in bacterial invasion of host tissues.

We invest in NIH each year to expand our vital scientific knowledge, but also to create real world products that protect our communities. In February, for example, researchers launched early-stage clinical trials of two candidate vaccines against *Shigella* infection, which each year causes about 90 million cases of severe diarrheal illness and 108,000 deaths worldwide. Others are working toward broad spectrum antivirals effective against groups of pathogens, like that being developed against all enveloped viruses, including the Nipah, Ebola, HIV, influenza, and Rift Valley fever viruses. NIH also is supporting development of new technologies like nanoscience techniques to detect pathogens hidden deep in human tissue and genome sequencing to better track infectious disease outbreaks.

NIH Funding Stimulates Economic Sector, Workforce Expansion

Biomedicine is big business—the U.S. medical innovation sector employs 1 million U.S. citizens, generates \$84 billion in wages and salaries, and exports \$90 billion in goods and services. Yet U.S. industry performs only 17 percent of basic research, leaving most of the biomedical “foundation building” to Federal responsibility. NIH is the largest funder of biomedical research in the world, including the research of 138 Nobel Prize winners. It contributes more than 80 percent of Federal biomedical research funding in the United States. The NIH extramural program supports about 50,000 competitive research grants and 300,000 scientists and research personnel at more than 2,500 medical schools, universities, and other institutions throughout the country. Annual appropriations also support nearly 6,000 scientists working at the 27 NIH institutes and centers. The UMR analysis released in February reinforced the agency’s importance as an economic motive force. In 2012 alone, the NIH financed more than 402,000 jobs and \$57.8 billion in economic output nationwide.

Investment in NIH clearly reaps rewards well beyond improved public health. Since 2000, for example, NIGMS supported research has received 18 Nobel Prizes

either in Chemistry or in Physiology or Medicine. In December, NIH proposed multiple initiatives to help strengthen both the U.S. biomedical research enterprise and the Nation's global competitiveness, designed "to support a research ecosystem that leverages the flood of biomedical data, strengthens the research workforce through diversity, and attracts the next generation of researchers." To be successful, initiative strategies like enhanced training of graduate students and better management of "big data" through high performance computing will require sufficient funding increases.

NIH support for university research has long been a major factor in scientific and technological innovation in medicine. Unfortunately, the current fiscal scenario will force reductions in existing grants and likely fewer new awards going forward. Scientists at U.S. universities are already reporting sequestration related setbacks to their planned research, casting doubt on both potential breakthroughs and student training programs. Stakeholders in biomedical research are concerned that among the research jobs at risk, younger scientists will be particularly affected. Undermining a future workforce generation is shortsighted, and the ASM fears subsequent negative impacts on new R&D discoveries, public health, and U.S. global competitiveness.

The ASM urgently requests the Congress increase funding for the NIH and biomedical research.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR NUTRITION

Dear Chairman Harkin and Ranking Member Moran: The American Society for Nutrition (ASN) respectfully requests \$32 billion for the National Institutes of Health (NIH) and \$162 million for the Centers for Disease Control and Prevention/National Center for Health Statistics (CDC/NCHS) in fiscal year 2014. ASN is dedicated to bringing together the world's top researchers to advance our knowledge and application of nutrition. ASN has nearly 5,000 members working throughout academia, clinical practice, Government, and industry, who conduct research to help all Americans live healthier, more productive lives.

NATIONAL INSTITUTES OF HEALTH

The National Institutes of Health (NIH) is the Nation's premier sponsor of biomedical research and is the agency responsible for conducting and supporting 86 percent (approximately \$1.4 billion) of federally-funded basic and clinical nutrition research. Nutrition research, which makes up about 4 percent of the NIH budget, is truly a trans-NIH endeavor, being conducted and funded across multiple Institutes and Centers. Some of the most promising nutrition-related research discoveries have been made possible by NIH support. In order to fulfill the full potential of biomedical research, including nutrition research, ASN recommends an fiscal year 2014 funding level of \$32 billion for the NIH, a modest increase over the current funding level of \$30.64 billion.

The modest increase we recommend is necessary to maintain both the existing and future scientific infrastructure. The discovery process—while it produces tremendous value—often takes a lengthy and unpredictable path. Economic stagnation is disruptive to training, careers, long range projects and ultimately to progress. NIH needs sustainable and predictable budget growth to achieve the full promise of medical research and to improve the health of all Americans. It is imperative that we continue our commitment to biomedical research and continue our Nation's dominance in this area by making the NIH a national priority.

Over the past 50 years, NIH and its grantees have played a major role in the growth of knowledge that has transformed our understanding of human health, and how to prevent and treat human disease. Because of the unprecedented number of breakthroughs and discoveries made possible by NIH funding, scientists are helping Americans to live healthier and more productive lives. Many of these discoveries are nutrition-related and have impacted the way clinicians prevent and treat heart disease, cancer, diabetes and other chronic diseases. By 2030, the number of Americans age 65 and older is expected to grow to 72 million, and the incidence of chronic disease will also grow. Sustained support for basic and clinical research is required if we are to successfully confront the health care challenges associated with an older, and potentially sicker, population.

CDC NATIONAL CENTER FOR HEALTH STATISTICS

The National Center for Health Statistics (NCHS), housed within the Centers for Disease Control and Prevention, is the Nation's principal health statistics agency.

The NCHS provides critical data on all aspects of our health care system, and it is responsible for monitoring the Nation's health and nutrition status through surveys such as the National Health and Nutrition Examination Survey (NHANES), that serve as a gold standard for data collection around the world. Nutrition and health data, largely collected through NHANES, are essential for tracking the nutrition, health and well-being of the American population, and are especially important for observing nutritional and health trends in our Nation's children.

Nutrition monitoring conducted by the Department of Health and Human Services in partnership with the U.S. Department of Agriculture/Agricultural Research Service is a unique and critically important surveillance function in which dietary intake, nutritional status, and health status are evaluated in a rigorous and standardized manner. Nutrition monitoring is an inherently governmental function and findings are essential for multiple Government agencies, as well as the public and private sector. Nutrition monitoring is essential to track what Americans are eating, inform nutrition and dietary guidance policy, evaluate the effectiveness and efficiency of nutrition assistance programs, and study nutrition-related disease outcomes. Funds are needed to ensure the continuation of this critical surveillance of the Nation's nutritional status and the many benefits it provides.

Through learning both what Americans eat and how their diets directly affect their health, the NCHS is able to monitor the prevalence of obesity and other chronic diseases in the U.S. and track the performance of preventive interventions, as well as assess 'nutrients of concern' such as calcium, which are consumed in inadequate amounts by many subsets of our population. Data such as these are critical to guide policy development in the area of health and nutrition, including food safety, food labeling, food assistance, military rations and dietary guidance. For example, NHANES data are used to determine funding levels for programs such as the Supplemental Nutrition Assistance Program (SNAP) and the Women, Infants, and Children (WIC) clinics, which provide nourishment to low-income women and children.

To continue support for the agency and its important mission, ASN recommends an fiscal year 2014 funding level of \$162 million for NCHS. Sustained funding for NCHS can help to ensure uninterrupted collection of vital health and nutrition statistics, and will help to cover the costs needed for technology and information security upgrades that are necessary to replace aging survey infrastructure.

Thank you for the opportunity to submit testimony regarding fiscal year 2014 appropriations for the National Institutes of Health and the CDC/National Center for Health Statistics. Please contact John E. Courtney, Ph.D., Executive Officer, if ASN may provide further assistance. He can be reached at 9650 Rockville Pike, Bethesda, Maryland 20814; or jcourtney@nutrition.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR PHARMACOLOGY &
EXPERIMENTAL THERAPEUTICS

The American Society for Pharmacology and Experimental Therapeutics (ASPET) is pleased to submit written testimony in support of the National Institutes of Health (NIH) fiscal year 2014 budget. ASPET recommends a budget of at least \$32 billion for the NIH in fiscal year 2014.

Sustained growth for the NIH should be an urgent national priority. Research funded by the NIH improves public health, stimulates our economy and improves global competitiveness. Several years of flat funding and mandatory budget cuts required by sequestration in the current fiscal year prevents and delays advances in medical research, jeopardizes potential cures and eliminates jobs. Additionally, the Nation will lose a generation of young scientists who see no prospects for careers in biomedical research, creating a "brain drain" as many graduate students, post-doctoral researchers, and early career scientists leave the research enterprise or look for employment in foreign countries.

The 5 percent sequestration cut further diminishes NIH's research capacity that has already fallen 20 percent since 2003 as a result of flat funding and inflation. With sequestration, NIH's purchasing power will be reduced by nearly 25 percent since 2003. Continued erosion of NIH's research capacity will accelerate further the diminishment of American leadership and innovation in biomedical research. Without a commitment to sustained funding for the NIH, the Nation's biomedical research capacity will erode further.

A \$32 billion budget for the NIH in fiscal year 2014 is a start to help restore NIH's biomedical research capacity. Currently, the NIH only can fund one in six grant applications, the lowest rate in the agency's history. Furthermore, the number of research project grants funded by NIH has declined every year since 2004.

A budget of at least \$32 billion in fiscal year 2014 will help the agency manage its research portfolio effectively without having to withhold funding for existing grants to researchers throughout the country. Scientific research takes time. Only through steady, sustained and predictable funding increases can NIH continue to fund the highest quality biomedical research to help improve the health of all Americans and continue to make significant economic impact in many communities across the country.

There is no substitute for a steady, sustained Federal investment in biomedical research. Industry, venture capital, and private philanthropy can supplement research but cannot replace the investment in basic, fundamental biomedical research provided by NIH. Industry and venture capital both face their own economic challenges and venture capital investment in biomedicine has declined since 2007. Neither the private sector nor industry will be able to fill a void for NIH funded basic biomedical research. Much of industry support is applied research that builds upon the discoveries generated from NIH-funded projects. The majority of the investment in basic biomedical research that NIH provides is broad and long-term providing a continuous development platform for industry, which would not typically invest in research that may be of higher risk and require several years to fully mature. In addition to this long term view, NIH also has mechanisms in place to rapidly build upon key technologies and discoveries that have the ability to have significant impact on the health and well being of our citizens. Further, industry research is focused on developing drugs that are protected by patents and often does not make their data publicly available.

Many of the basic science initiatives supported by NIH have led to totally unexpected discoveries and insight that have transformed our mechanistic understanding of and our ability to treat a wide range of diseases

Diminished Support for NIH will Negatively Impact Human Health

Continued diminishment of funding for NIH will mean a loss of scientific opportunities to discover new therapeutic targets. Without a steady, sustained Federal investment in fundamental biomedical research, scientific progress will be slower and potentially helpful therapies or cures will not be developed. For example, more research is needed on Parkinson's disease to help identify the causes of the disease and help develop better therapies; discovery of gene variations in age-related macular degeneration could result in new screening tests and preventive therapies; more basic research is needed to focus on new molecular targets to improve treatment for Alzheimer's disease; and diminished support for NIH will prevent new and ongoing investigations into rare diseases that FDA estimates almost 90 percent are serious or life-threatening.

Historically, our past investment in basic biological research has led to many innovative medicines. The National Research Council reported that of the 21 drugs with the highest therapeutic impact, only five were developed without input from the public sector. The significant past investment in the NIH has provided major gains in our knowledge of the human genome, resulting in the promise of pharmacogenomics and a reduction in adverse drug reactions that currently represent a major worldwide health concern. Several completed human genome sequence analyses have pinpointed disease-causing variants that have led to improved therapy and cures but further advances and improvements in technology will be delayed or obstructed with inadequate NIH funding.

Investing in NIH Helps America Compete Economically

A \$32 billion budget in fiscal year 2013 will also help the NIH train the next generation of scientists and provide a platform for broader workforce development that is so critical to our Nation's growth. Many individuals trained in the sciences via NIH support become educators in high schools and colleges. These individuals also enter into other aspects of technology development and evaluation in public and private sectors to further enrich the community and accelerate economic development.

This investment will help to create jobs and promote economic growth. Limiting or cutting the NIH budget will mean forfeiting future discoveries and jobs to other countries.

The U.S. share of global research and development investment from 1999–2009 is now only 31 percent, a decline of 18 percent. In contrast, other nations continue to invest aggressively in science. China has grown its science portfolio with annual increases to the research and development budget averaging over 23 percent annually since 2000, including a 26 percent increase in 2012. Russia plans to increase support for research by 65 percent over the next 5 years. And while Great Britain 2 years ago also imposed strict austerity measures to address that Nation's debt problems, that Nation had the foresight to keep its strategic investments in science

at current levels. The European Union, despite great economic distress and the severe debt problems of its member nations, has proposed to increase spending on research and innovation by 45 percent between 2014 and 2020.

NIH research funding catalyzes private sector growth. More than 83 percent of NIH funding is awarded to over 3,000 universities, medical schools, teaching hospitals and other research institutions in every State. One national study by an economic consulting firm found that Federal (and State) funded research at the Nation's medical schools and hospitals supported almost 300,000 jobs and added nearly \$45 billion to the U.S. economy. NIH funding also provides the most significant scientific innovations of the pharmaceutical and biotechnology industries.

CONCLUSION

ASPET appreciates the many competing and important spending decisions the subcommittee must make. The Nation's deficit and debt problems are great. However, NIH and the biomedical research enterprise face a critical moment. The agency's contribution to the Nation's economic and physical well being should make it one of the Nation's top priorities. With enhanced and sustained funding, NIH can begin to reverse its decline and help meet its potential to address many of the more promising scientific opportunities that currently challenge medicine. A budget of at least \$32 billion in fiscal year 2014 will allow the agency to begin moving forward to full program capacity, exploiting more scientific opportunities for investigation, and increasing investigator's chances of discoveries that prevent, diagnose and treat disease. NIH should be restored to its role as a national treasure, one that attracts and retains the best and brightest to biomedical research and provides hope to millions of individuals afflicted with illness and disease.

ASPET is a 5,100 member professional society whose members conduct basic, translational, and clinical pharmacological research within the academic, industrial and Government sectors. Our members discover and develop new medicines and therapeutic agents that fight existing and emerging diseases, as well as increase our knowledge regarding how therapeutics affects humans.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF HEMATOLOGY

The American Society of Hematology (ASH) thanks the subcommittee for the opportunity to submit written testimony on the fiscal year 2014 Departments of Labor, Health and Human Services, and Education Appropriations bill.

ASH represents approximately 14,000 clinicians and scientists committed to the study and treatment of blood and blood-related diseases. These diseases encompass malignant disorders such as leukemia, lymphoma, and myeloma; life-threatening conditions, including thrombosis and bleeding disorders; and congenital diseases such as sickle cell anemia, thalassemia, and hemophilia. In addition, hematologists have been pioneers in the fields of bone marrow transplantation, stem cell biology and regenerative medicine, gene therapy, and the development of many drugs for the prevention and treatment of heart attacks and strokes.

Funding for Hematology Research: An Investment in the Nation's Health

Over the past 60 years, American biomedical research has led the world in probing the nature of human disease. This research has led to new medical treatments, saved innumerable lives, reduced human suffering, and spawned entire new industries. This research would not have been possible without support from the National Institutes of Health (NIH). NIH-funded research drives medical innovation that improves health and quality of life through new and better diagnostics, improved prevention strategies, and more effective treatments. Federal funding of basic biomedical research through the NIH is crucial, as most of this discovery-based research is not supported by philanthropy or private industry. Discoveries gained through basic research yield the medical advances that improve the fiscal and physical health of the country.

Funding for hematology research has been an important component of this investment in the Nation's health. Most of the research that produced cures and treatments for hematologic diseases has been funded by the NIH. The study of blood and its disorders is a trans-NIH issue involving many institutes at the NIH, including the National Heart, Lung and Blood Institute (NHLBI), the National Cancer Institute (NCI), the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK), and the National Institute on Aging (NIA).

With the advances gained through an increasingly sophisticated understanding of how the blood system functions, hematologists have changed the face of medicine through their dedication to improving the lives of patients. As a result, children are

routinely cured of acute lymphoblastic leukemia (ALL); more than 90 percent of patients with acute promyelocytic leukemia (APL) are cured with a drug derived from vitamin A; older patients suffering from previously lethal chronic myeloid leukemia (CML) are now effectively treated with well-tolerated pills; and patients with multiple myeloma are treated with new classes of drugs.

Hematology advances also help patients with other types of cancers, heart disease, and stroke. Blood thinners effectively treat or prevent blood clots, pulmonary embolism, and strokes. Death rates from heart attacks are reduced by new forms of anticoagulation drugs. Stem cell transplantation can cure not only blood diseases but also inherited metabolic disorders, while gene therapy holds the promise of effectively treating even more genetic diseases. Even modest investments in hematology research have yielded large dividends for other disciplines.

The Future Promise of Hematology Research

The era of precision medicine has arrived. Insights into new genetic and biologic markers can be used to understand what causes a disease, the risk factors that predispose to disease, and how patients will respond to a particular treatment. Translating these new discoveries and technologies into personalized patient care offers the possibility of better survival, less toxicity, disease prevention, improved quality of life, and lower health-care costs. However, many patients still lack effective therapy for malignant and non-malignant hematologic diseases.

Research funding must increase to allow the major advances in understanding the molecular defects behind hematologic diseases to be translated into novel diagnostics and targeted therapeutics. Support for research in the areas listed below will be important for future progress:

- Stem Cells and Regenerative Medicine: Turn iPS cells into cures for human diseases
- Myelodysplastic Syndrome and Acute Myeloid Leukemia: Find an effective and personalized treatment for the elderly
- Hematopoietic Stem Cell Transplantation: Increase success rates by improving management of graft-versus-host disease
- Sickle Cell Disease: Reduce the barriers to care, burden of pain, end-organ injury, and premature death
- Deep-Vein Thrombosis and Venous Thromboembolism: Understand the risk factors and develop targeted therapies
- Childhood Leukemia: Improve cure rates by performing coordinated research that includes discovery and preclinical and clinical testing of novel targeted therapies
- Translating Laboratory Advances into the Clinic: Use novel genomic technologies to improve treatment of hematologic diseases

Sequestration Threatens Scientific Momentum

ASH is particularly concerned about the impact of continued cuts on biomedical research supported by the NIH. At a time when we should be investing more in research to save more lives, research funding is in serious jeopardy.

After a decade of flat funding, the NIH budget after inflation is about 20 percent lower than it was in 2003. ASH is deeply disturbed about the impact that this effective “un-doubling” of the NIH budget, combined with the more than 5 percent cut in NIH funding under sequestration in the current fiscal year and additional planned cuts in future fiscal years, will have on the ability to sustain the scientific momentum that has contributed so greatly to our Nation’s health and our economic vitality. NIH’s ability to continue current research capacity and encourage promising new areas of science is, and will be, significantly limited. Sequestration will result in cuts in extramural grants and slowing momentum for the development of new treatments, or even cures, for seriously ill patients with deadly diseases.

Additionally, perhaps one of the greatest concerns is the obstacle these continued cuts will present to the next generation of scientists, who will see training funds slashed and the possibility of sustaining a career in research diminished. NIH also plays a significant role in supporting the next generation of innovators, the young and talented scientists and physicians who will be responsible for the breakthroughs of tomorrow. The Society is especially concerned about the number of scientists who have abandoned research careers; continued cuts will exacerbate this exodus, forcing researchers to abandon potentially life-enhancing research, negatively affecting job creation, and seriously jeopardizing America’s leadership in medical research throughout the world.

Fiscal Year 2014 NIH Funding Request

ASH supports the recommendation of the Ad Hoc Group for Medical Research that the subcommittee recognize NIH as a critical national priority by providing at

least \$32 billion in funding in the fiscal year 2014 Labor-HHS-Education Appropriations bill. This funding recommendation represents the minimum investment necessary to avoid further loss of promising research and at the same time allows the NIH's budget to keep pace with biomedical inflation.

Hematology research offers enormous potential to better understand, prevent, treat, and cure a number of blood-related and other conditions. Recent investments have created dramatic new research opportunities, spurring advancements and precipitating the promise of personalized medicine that will yield far-reaching health and economic benefits. Trials to find new therapies and cures for millions of Americans with blood cancers, bleeding disorders, clotting problems, and genetic diseases are just a few of the important projects that could be delayed unless NIH continues to receive predictable and sustained funding.

It is critically important that our country continues to capitalize on the momentum of previous investments to drive research progress to develop new treatments for serious disorders, train the next generation of scientists, create jobs, and promote economic growth and innovation. Adequate funding is necessary for NIH to sustain current research capacity and encourage promising new areas of science and cures.

While ASH recognizes the deficit and the increasing debt the country faces will require difficult decisions, it is also important to understand that Federal investment in research and public health programs saves lives, reduces health costs and strengthens the Nation. Funding for hematology research is an investment in the Nation's health. Research funding must increase to allow the major advances in understanding the molecular defects behind hematologic diseases to be translated into novel diagnostics and targeted therapeutics not only for blood disorders, but other life-threatening diseases. ASH urges the subcommittee to continue to be a champion for research and support at least \$32 billion in funding for NIH in fiscal year 2014. The American people are depending on you to ensure the Nation does not lose the health and economic benefits of our extraordinary commitment to biomedical research.

Centers for Disease Control and Prevention (CDC) Public Health Response for Blood Disorders

The Society also recognizes the important role of the Centers for Disease Control and Prevention (CDC) in preventing and controlling clotting, bleeding, and other hematologic disorders. Blood disorders—such as sickle cell disease, anemia, blood clots, and hemophilia—are a serious public health problem and affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. Men, women, and children of all backgrounds live with the complications associated with these conditions, many of which are painful and potentially life-threatening.

Through the Division of Blood Disorders in the Center on Birth Defects and Developmental Disabilities (NCBDDD), CDC is working toward developing a comprehensive public health agenda to promote and improve the health of people with blood disorders. As a key component of this public health approach, CDC staff invest in identifying, monitoring, diagnosing, and investigating blood disorders to understand the prevalence and effect of these disorders. Charting the characteristics and outcomes of a disease population, such as those with sickle cell disease or hemophilia, can provide insight into these questions, as well as help identify the quality and cost of care issues that people who are affected face. Additionally, population-based studies can increase our understanding of risk factors that can result in severe complications for people with blood disorders.

CDC is uniquely positioned to reduce the public health burden resulting from blood disorders by contributing to a better understanding of these conditions and their complications; ensuring that prevention programs are developed, implemented, and evaluated; ensuring that information is accessible to consumers and health care providers; and encouraging action to improve the quality of life for people living with or affected by these conditions. The Society is supportive of maintaining the programs funded by the Division of Blood Disorders and supports the requested budget authority of \$20,672,000 for the Public Health Approach to Blood Disorders in the President's fiscal year 2014 budget request. This funding will allow CDC to improve health outcomes and limit complications to those who are at risk or currently have blood disorders, by promoting a comprehensive care model; identifying and evaluating effective prevention strategies; and increasing public and healthcare provider awareness of bleeding and clotting disorders such as hemophilia and thrombosis, and hemoglobinopathies, including sickle cell disease and thalassemia.

Thank you again for the opportunity to submit testimony. Please contact Tracy Roades, ASH Legislative Advocacy Manager, at troades@hematology.org, if you have

any questions or need further information concerning hematology research or ASH's fiscal year 2014 funding request.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF NEPHROLOGY

EXECUTIVE SUMMARY

The American Society of Nephrology (ASN) requests \$32 billion in funding for the National Institutes of Health (NIH) and \$2 billion in funding for NIH's National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in the fiscal year 2014 Labor-HHS-Education Appropriations bill.

ASN is dedicated to the study, prevention, and treatment of kidney disease, and the society's 14,000 plus members greatly respect your leadership and commitment to preventing illness, treating disease, and maintaining fiscal responsibility. Chronic kidney disease (CKD) currently affects more than 20 million Americans, and more than 570,000 of them have irreversible kidney failure requiring life-sustaining treatment with regular dialysis therapies.

The vast majority of research leading to advances in the care and treatment of adults and children afflicted with kidney disease is funded by the National Institutes of Health (NIH) broadly and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) specifically. Any reduction in this funding would seriously reduce our ability to contain and reverse this disease, which costs Americans enormous suffering, lost productivity, and foreshortened spans of life.

Examples of critical discoveries arising from NIH-funded research are numerous. For instance, investigative studies supported by NIH and NIDDK led to a groundbreaking discovery that helps explain racial/ethnic disparities that increase risks for kidney disease, which can lead to earlier detection and treatment. The recent finding that African Americans with two variants of the APOL1 gene are likely to experience faster decline in kidney function, and earlier initiation of hemodialysis than their peers without the gene, is a crucial step in understanding differences in kidney disease progression across different populations and how early interventions may improve their outcomes.

Scientists supported by NIH and NIDDK also identified mutations in two genes that help regulate blood pressure and salt balance in a rare, heritable disease that causes high blood pressure, or hypertension. Hypertension is a leading contributor to the development of kidney failure, so this finding may improve hypertension management in patients with kidney disease—possibly preventing kidney failure—and could lead to better therapies for controlling high blood pressure in the general patient population.

Moreover, funding from NIH and NIDDK enabled research that found that people with antibodies that target a protein [the phospholipase A2 receptor called PLAR2] on a specific kidney cell develop a kidney disorder, known as nephrotic syndrome that results in a harmful excess protein in urine. Future therapies that reduce PLAR2 antibody levels may help prevent people with nephrotic syndrome from progressing to kidney failure.

Dialysis is covered by Medicare regardless of a patient's age or disability status. Consequently, preventing kidney disease and advancing the effectiveness of therapies for kidney failure—starting with innovative research at NIDDK—would have a great impact at the highest level of costs within the Centers for Medicare and Medicaid Services. Perhaps most important, in human terms, the applied research will help prevent greater suffering among those who would otherwise progress to an even greater level of illness.

Sustained, predictable investment in research is the only way that scientific investigations can be effective and lead to new discoveries. With funding from NIH and NIDDK, scientists have been able to pursue cutting-edge basic, clinical, and translational research. While ASN fully understands the difficult economic environment and the intense pressure you are under as an elected official to guide America forward during these tough times, the society firmly believes that funding NIH and NIDDK is a good investment to create jobs, support the next generation of investigators, and ultimately improve the public health of Americans.

Several recent studies have concluded that Federal support for medical research is a major force in the economic health of communities across the Nation.

It is critically important that the Nation continue to capitalize on previous investments to drive research progress, train the next generation of scientists, create new jobs, promote economic growth, and maintain leadership in the global innovation economy—particularly as other countries increase their investments in scientific research. Most important, a failure to maintain and strengthen NIH and NIDDK's

ability to support the groundbreaking work of researchers across the country carries a palpable human toll, denying hope to the millions of patients awaiting the possibility of a healthier tomorrow.

ASN strongly recommends that the fiscal year 2014 Labor-HHS-Education Appropriations bill uphold its longstanding legacy of bipartisan support for biomedical research.

Should you have any questions or wish to discuss NIH, NIDDK, or kidney disease research in more detail, please contact ASN Manager of Policy and Government Affairs Rachel Shaffer at rshaffer@asn-online.org.

ABOUT ASN

The American Society of Nephrology (ASN) is a 501(c)(3) non-profit, tax-exempt organization that leads the fight against kidney disease by educating the society's more than 14,000 physicians, scientists, and other healthcare professionals, sharing new knowledge, advancing research, and advocating the highest quality care for patients. For more information, visit ASN's website at www.asn-online.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

I am Dr. Joseph Flynn, President of the American Society of Pediatric Nephrology (ASPN). I am pleased to submit written testimony on behalf of the ASPN in support of Federal funding for the National Institutes of Health, including the National Institutes for Diabetes, Digestive and Kidney Diseases (NIDDK) and Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD). In fiscal year 2014 we urge you to support an appropriation of \$32 billion for the NIH, including at least \$2.03 billion for NIDDK and \$1.37 billion for NICHD.

Founded in 1969, the American Society for Pediatric Nephrology (ASPN) is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. The ASPN currently has over 700 members, making it the primary representative of the pediatric nephrology community in North America.

The mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is to support and conduct research to combat diabetes and other endocrine and metabolic diseases, liver and other digestive diseases, nutritional disorders, obesity, and kidney, urologic, and hematologic diseases. The NIDDK's broad mission covers chronic, common and costly diseases that have very tangible monetary consequences for our Nation. For example, estimates of chronic kidney disease (CKD) show that more than 23 million Americans are affected, and over 550,000 have irreversible end-stage renal disease (ESRD). ESRD's cost to our bottom line is also felt at the Centers for Medicare and Medicaid Services, as ESRD is covered by Medicare regardless of a patient's age. NIDDK-funded investigations intended to prevent this disease would have a significant impact on many Americans.

Without research funded by the NIH and NIDDK, advances in the care and treatment of adults and children afflicted with kidney disease would not have been accomplished. For instance, hereditary diseases such as cystinosis—a metabolic disorder that affects the kidneys, eyes, thyroid, pancreas, and brain—can now be treated so as to prevent or delay its worst effects on children. The NIDDK supports a wide range of medical research through grants to universities and other medical research institutions across the country. The Institute also supports Government scientists who conduct basic, translational, and clinical research across a broad spectrum of research topics and serious, chronic diseases and conditions related to the Institute's mission. In addition, the NIDDK supports research training for students and scientists at various stages of their careers and a range of education and outreach programs to bring science-based information to patients and their families, health care professionals, and the public. Developing the next generation of researchers through grant support will solidify future novel therapeutics and improved outcomes for children with kidney disease.

Established in 1963, the NICHD was initially founded to support the world's best minds in investigating human development throughout the entire lifespan, focusing on understanding developmental disabilities, including intellectual and developmental disabilities, and illuminating important events that occur during pregnancy. Since then, the NICHD has achieved an impressive array of scientific advances in its pursuit to enhance lives throughout all stages of human development, from pre-conception through adulthood, improving the health of children, adults, families, communities, and populations. Recent efforts by the NICHD to improve the availability and safety of drugs for children will have significant impact on pediatric

therapeutics. Research supported and conducted by the NICHD has helped to explain the unique health needs of many, and has brought about novel and effective ways to fulfill them. An estimated 150,000 children and adolescents currently suffer from kidney disease; about 10,000 of them suffer from ESRD and receive chronic dialysis or have a kidney transplant. Children and adolescents undergoing dialysis or transplants are different from adults, with different underlying diseases, dependence on adult caregivers, and ongoing growth and development. Renal transplantation is the best treatment for children who reach ESRD, as transplant allows better growth and school attendance and a more normal life for affected children and families. The ASPN works to educate the public, Members of Congress and their staffs, and the medical community about these unique needs of pediatric patients with kidney disease. Nonetheless, without adequate funding from the NIH, pediatric nephrologists are unable to focus on this challenging pediatric population.

The ASPN supports improving the quality of life for pediatric kidney patients, especially those with kidney transplants, through the following initiatives:

Increased research focused on the prevention and early identification of pediatric kidney disease to decrease the growing need for renal transplantation.—The dramatic increase in childhood obesity puts more than 15 percent of America's children at risk for Type 2 diabetes, hypertension, and chronic kidney disease later in life. The fastest growing segment of patients waiting for a kidney transplant today have ESRD related to complications of diabetes and hypertension, making it ever more difficult to keep up with the demand for kidney transplants. The ASPN advocates for more research to address ways to keep children with Type 2 diabetes and hypertension from becoming adolescents and young adults with ESRD. We also advocate for additional research to investigate the common causes of CKD and ESRD including progressive glomerular diseases and congenital anomalies of the kidney and urinary tract. Furthermore, we strongly support investigations into common sequelae of CKD and ESRD such as acidosis and kidney stones as well as those that can accelerate the progression from CKD to ESRD such as urinary tract infections, toxins, and acute kidney injury.

Improved transition of patients from pediatric to adult medical care.—The ASPN collaborates with pediatric and adult nephrology professionals to improve the transition of adolescents to adult care. The ASPN advocates for better access to medical insurance coverage and anti-rejection medications for transitioning patients to help reduce the high incidence of loss of transplant function in adolescents and young adults. Kidney disease continues to be a major cause of illness and death among the most vulnerable segment of the population—our children—and research being conducted at the NIH will allow us to better understand how to reduce its impact. An estimated 150,000 children and adolescents currently suffer from kidney diseases for which a cure or treatment does not exist; about 10,000 of them suffer from ESRD and are on dialysis or have a kidney transplant. With adequate funding for NIH, scientists will work to find cures or more effective treatments.

We urge you to support the work conducted by NIDDK for research focused on pediatric kidney disease. ASPN is enthusiastic and encouraged by the discoveries made by such research. Because many adult kidney diseases originate prenatally or during childhood, we hope you can support NIDDK efforts to assign a higher priority to research that explores pediatric renal disease, focusing on the causes, outcomes and consequences of such diseases. Due to the unique challenges of recruiting children into clinical trials, NIDDK should fund research endeavors that include support for infrastructure and the enhancement of collaborative and comparative multicenter pediatric prospective clinical/translational trials that aim to improve patient outcomes.

Additionally, normal child development is essential for promoting a healthy adult society. Diseases that pose a substantial burden in adults, such as hypertension and chronic kidney disease, may have their origins during childhood years or may be patterned in early fetal life. Cognitive development and cardiovascular health in children, which depend upon normal physiology, are essential for healthy, productive adult outcomes. Yet the importance of normal kidneys to normal intrauterine and childhood growth, and its impact on the risk of subsequent disease later in life, has not been well studied. We urge you to support collaboration between NICHD and NIDDK to undertake efforts to examine the role of normal kidney development and/or function in neonatal and child health. Specific opportunities to be addressed include: kidney function in low-birth weight infants; how chronic acidosis, untreated hypertension or recurrent urinary tract infections affect child development; the impact of childhood onset hypertension on adult cardiovascular health; and identification of genetic factors that may result in kidney injury and progression of hypertension and chronic kidney disease.

Thank you for the opportunity to provide testimony in support of these vital programs. We look forward to continuing to work with you in the future on these important issues.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF PLANT BIOLOGISTS

On behalf of the American Society of Plant Biologists (ASPB), we would like to thank the subcommittee for its support of the National Institutes of Health (NIH). ASPB and its members strongly believe that sustained investments in scientific research will be a critical step toward economic recovery and job creation in our Nation. ASPB asks that the subcommittee Members encourage increased support for plant-related research within NIH; 25 percent of our medicines originate from discoveries related to plant natural products, and such research has contributed in innumerable ways to improving the lives and health of Americans and people throughout the world.

ASPB is an organization of some 4,500 professional plant biology researchers, educators, students, and postdoctoral scientists with members across the Nation and throughout the world. A strong voice for the global plant science community, our mission—achieved through work in the realms of research, education, and public policy—is to promote the growth and development of plant biology, to encourage and communicate research in plant biology, and to promote the interests and growth of plant scientists in general.

Plant Biology Research and America's Future

Among many other functions, plants form much of the base of the food chain upon which all life depends. Importantly, plant research is also helping make many fundamental contributions in the area of human health, including that of a sustainable supply and discovery of plant-derived pharmaceuticals, nutraceuticals, and alternative medicines. Plant research also contributes to the continued, sustainable, development of better and more nutritious foods and the understanding of basic biological principles that underpin improvements in the health and nutrition of all Americans.

Plant Biology and the National Institutes of Health

Plant science and many of our ASPB member research activities have enormous positive impacts on the NIH mission to pursue “fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability.” In general, plant research aims to improve the overall human condition—be it food, nutrition, medicine or agriculture—and the benefits of plant science research readily extend across disciplines. In fact, plants are often the ideal model systems to advance our “fundamental knowledge about the nature and behavior of living systems” as they provide the context of multi-cellularity while affording ease of genetic manipulation, a lesser regulatory burden, and maintenance requirements that are less expensive than those required for the use of animal systems.

Many fundamental biological components and mechanisms (e.g., cell division, viral and bacterial invasion, polar growth, DNA methylation and repair, innate immunity signaling and circadian rhythms) are shared by both plants and animals. For example, a process known as RNA interference, which has potential application in the treatment of human disease, was first discovered in plants. Subsequent research eventually led to two American scientists, Andrew Fire and Craig Mello, earning the 2006 Nobel Prize in Physiology or Medicine. More recently scientists engineered a class of proteins called TALENs capable of precisely editing genomes to potentially correct mutations that lead to disease. That these therapeutic proteins are derived from others initially discovered in a plant pathogen exemplifies the application of plant biology research to improving human health. These important discoveries again reflect the fact that some of the most important biological discoveries applicable to human physiology and medicine can find their origins in plant-related research endeavors.

Health and Nutrition.—Plant biology research is also central to the application of basic knowledge to “extend healthy life and reduce the burdens of illness and disability.” Without good nutrition, there cannot be good health. Indeed, a World Health Organization study on childhood nutrition in developing countries concluded that over 50 percent of child deaths under the age of five could be attributed to malnutrition’s effects in weakening the immune system and exacerbating common illnesses such as respiratory infections and diarrhea. Strikingly, most of these deaths were not linked to severe malnutrition, but chronic nutritional deficiencies brought about by overreliance on single crops for primary staples. Plant researchers are

working today to address the root cause of this problem by balancing the nutritional content of major crop plants to provide the full range of essential micronutrients in plant-based diets.

By contrast to developing countries, obesity, cardiac disease, and cancer take a striking toll in the developed world. Research to improve and optimize concentrations of plant compounds known to have, for example, anti-carcinogenic properties, will hopefully help in reducing disease incidence rates. Ongoing development of crop varieties with tailored nutraceutical content is an important contribution that plant biologists can and are making toward realizing the long-awaited goal of personalized medicine, especially for preventative medicine.

Drug Discovery.—Plants are also fundamentally important as sources of both extant drugs and drug discovery leads. In fact, 60 percent of anti-cancer drugs in use within the last decade are of natural product origin—plants being a significant source. An excellent example of the importance of plant-based pharmaceuticals is the anti-cancer drug taxol, which was discovered as an anti-carcinogenic compound from the bark of the Pacific yew tree through collaborative work involving scientists at the NIH National Cancer Institute and plant natural product chemists. Taxol is just one example of the many plant compounds that will continue to provide a fruitful source of new drug leads.

While the pharmaceutical industry has largely neglected natural products-based drug discovery in recent years, research support from NIH offers yet another paradigm. Multidisciplinary teams of plant biologists, bioinformaticians, and synthetic biologists are being assembled to develop new tools and methods for natural products discovery and creation of new pharmaceuticals. We appreciate NIH's current investment into understanding the biosynthesis of natural products through transcriptomics and metabolomics of medicinal plants. The recently released "Genomes to Natural Products" funding opportunity is also to be applauded as a potential avenue for new plant-related medicinal research, and we strongly encourage the continuation of these types of investments and other plant-related initiatives which can help further achievement of the NIH mission.

Conclusion

Although NIH does recognize that plants serve many important roles, the boundaries of plant-related research are expansive and integrate seamlessly and synergistically with many different disciplines that are also highly relevant to NIH. As such, ASPB asks the subcommittee to provide direction to NIH to support additional plant research in order to continue to pioneer new discoveries and new methods with applicability and relevance in biomedical research.

Thank you for your consideration of our testimony on behalf of the American Society of Plant Biologists. For more information about ASPB, please see www.aspb.org.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

The American Society of Tropical Medicine and Hygiene (ASTMH)—the principal professional membership organization representing, educating, and supporting scientists, physicians, clinicians, researchers, epidemiologists, and other health professionals dedicated to the prevention and control of tropical diseases—appreciates the opportunity to submit testimony to the House Labor, Health and Human Services, and Education Appropriations Subcommittee. The benefits of U.S. investment in tropical diseases are both humanitarian and diplomatic. With this in mind, we respectfully request that the subcommittee fully fund the NIH and CDC in the fiscal year 2014 LHHs appropriations bill in order to ensure a continued U.S. investment in global health and tropical medicine research and development, specifically:

National Institutes of Health:

- Malaria and neglected tropical disease (NTD) treatment, control, and research and development efforts within the National Institute of Allergy and Infectious Diseases (NIAID);
- Expanded focus on diarrheal disease within the NIH;
- Research capacity development in countries where populations are at heightened risk for malaria, NTDs, and diarrheal diseases through the Fogarty International Center (FIC); and
- Research on infectious diseases transmitted by ticks, fleas, and mosquitoes that occur within the borders of the U.S. as well as in tropical and subtropical regions abroad.

The Centers for Disease Control and Prevention:

- The Center for Global Health, which includes CDC's work in malaria and NTDs; and
- The National Center for Emerging & Zoonotic Infectious Diseases, which is responsible for protecting the U.S. from new and emerging infections spread by mosquitoes and ticks.

RETURN ON INVESTMENT OF U.S.-FUNDED RESEARCH

CDC and NIH play essential roles in R&D for tropical medicine and global health. Both agencies are at the forefront of the new science that leads to tools to combat malaria and NTDs. This research provides jobs for American researchers and an opportunity for the U.S. to be a leader in the fight against global disease, in addition to creating lifesaving new drugs and diagnostics to some of the poorest, most at-risk people in the world.

TROPICAL DISEASE

Malaria and Parasitic Disease.—Malaria remains a global emergency affecting mostly poor women and children; it is an acute, sometimes fatal disease. Despite being treatable and preventable, malaria is one of the leading causes of death and disease worldwide. Approximately every 30 seconds, a child dies of malaria—a total of about 800,000 under the age of 5 every year. The World Health Organization (WHO) estimates that one half of the world's people are at risk for malaria and that there are 108 malaria-endemic countries.

Neglected Tropical Diseases.—NTDs are a group of chronic parasitic diseases, which represent the most common infections of the world's poorest people. These infections have been revealed as the stealth reason why the "bottom billion"—the 1.4 billion poorest people living below the poverty line—cannot escape poverty, because of the effects of these diseases on reducing child growth, cognition and intellect, and worker productivity.

Diarrheal Disease.—The child death toll due to diarrheal illnesses exceeds that of AIDS, tuberculosis, and malaria combined. In poor countries, diarrheal disease is second only to pneumonia as the cause of death among children under 5 years old. Every week, 31,000 children in low-income countries die from diarrheal diseases.

The United States has a long history of leading the fight against tropical diseases that cause human suffering and pose financial burden that can negatively impact a country's economic and political stability. Tropical diseases, many of them neglected for decades, impact U.S. citizens working or traveling overseas, as well as our military personnel. Additionally, some diseases such as dengue fever have been found in the U.S.

NATIONAL INSTITUTES OF HEALTH

National Institute of Allergy and Infectious Diseases.—A long-term investment is critical to achieve the drugs, diagnostics, and research capacity needed to control malaria and NTDs. NIAID is the lead institute for malaria and NTD research.

ASTMH encourages the subcommittee to:

- Increase funding for NIH to expand the agency's investment in malaria, NTDs, tick-borne infections, and diarrheal disease research and coordinate with other agencies to maximize resources and ensure development of basic discoveries into usable solutions;
- Specifically invest in NIAID to support its role at the forefront of these efforts to developing the next generation of drugs, vaccines, and other interventions; and
- Urge NIH to include enteric infections and neglected diseases in its RCDC process on the RePORT website to outline the work that is being done in these important research areas.

Fogarty International Center.—Biomedical research has provided major advances in the treatment and prevention of malaria, NTDs, and other infectious diseases. These benefits, however, are often slow to reach the people who need them most. FIC works to strengthen research capacity in countries where populations are particularly vulnerable to threats posed by malaria, NTDs, and other infectious diseases. This maximizes the impact of U.S. investments and is critical to fighting malaria and other tropical diseases.

ASTMH encourages the subcommittee to:

- Allocate sufficient resources to FIC in fiscal year 2014 to increase these efforts, particularly as they address the control and treatment of malaria, NTDs, and diarrheal disease.

THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Malaria and Parasitic Disease.—Malaria has been eliminated as an endemic threat in the United States for over fifty years, and CDC remains on the cutting edge of global efforts to reduce the toll of this deadly disease. CDC efforts on malaria and parasitic disease fall into three broad categories: prevention, treatment, and monitoring/evaluation of efforts. The agency performs a wide range of basic research within these categories, such as:

- Conducting research on antimalarial drug resistance to inform new strategies and prevention approaches;
- Assessing new monitoring, evaluation, and surveillance strategies;
- Conducting additional research on malaria vaccines, including field evaluations; and
- Developing innovative public health strategies for improving access to antimalarial treatment and delaying the appearance of antimalarial drug resistance.

ASTMH encourages the subcommittee to:

- Fund a comprehensive approach to effective and efficient malaria and parasitic disease, including adequately funding the important contributions of CDC in malaria and parasitic disease at no less than \$18 million.

Neglected Tropical Diseases.—CDC currently receives zero dollars directly for NTD work outside of parasitic diseases; however, this should be changed to allow for more comprehensive work to be done on NTDs at CDC. CDC has a long history of working on NTDs and has provided much of the science that underlies the global policies and programs in existence today.

ASTMH encourages the subcommittee to:

- Provide direct funding to CDC to continue its work on NTDs, including but not limited to parasitic diseases; and
- Urge CDC to continue its monitoring, evaluation, and technical assistance in these areas as an underpinning of efforts to control and eliminate these diseases.

Vector-Borne Disease Program (VBDP).—Through the VBDP, researchers are able to practice essential surveillance and monitoring activities that protect the U.S. from deadly infections before they reach our borders and to address problems of tick- and flea-transmitted infections such as Lyme disease and a dozen other infections, some of which are life-threatening within the U.S. The world is becoming increasingly smaller as international travel increases and new pathogens are introduced quickly into new environments. We have seen this with SARS, avian influenza, and now, dengue fever, in the United States. Arboviruses like dengue, and others, such as chikungunya, are a constant threat to travelers, and to Americans generally.

ASTMH encourages the subcommittee to:

- Ensure that CDC maintain these activities by continuing CDC funding for VBDP activities through the National Center for Emerging and Infectious Zoonotic Diseases.

CONCLUSION

Thank you for your attention to these important U.S. and global health matters. We know Congress and the American people face many challenges in choosing funding priorities, and we hope you will provide the requested fiscal year 2014 resources to those programs identified above that meet critical needs for Americans and people around the world. ASTMH appreciates the opportunity to share its expertise, and we thank you for your consideration of these requests that will help improve the lives of Americans and the global poor.

PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY

SUMMARY: FUNDING RECOMMENDATIONS

(In millions \$)

National Institutes of Health	32,000
National Heart, Lung & Blood Institute	3,214
National Institute of Allergy & Infectious Disease	4,701
National Institute of Environmental Health Sciences	717.7
Fogarty International Center	72.7
National Institute of Nursing Research	151
Centers for Disease Control and Prevention	7,800
National Institute for Occupational Safety & Health	293.6
Asthma Programs	25.3
Div. of Tuberculosis Elimination	243
Office on Smoking and Health	197.1
National Sleep Awareness Roundtable (NSART)	1

The American Thoracic Society (ATS) is pleased to submit our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview. Founded in 1905, the ATS is an international education and scientific society of 15,000 members that focuses on respiratory and critical care medicine. ATS members help prevent and fight respiratory disease through research, education, patient care and advocacy.

Lung Disease in America

Diseases of breathing constitute the third leading cause of death in the U.S., responsible for one of every seven deaths. Diseases affecting the respiratory (breathing) system include chronic obstructive pulmonary disease (COPD), lung cancer, tuberculosis, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, asthma, and critical illness. The death rate due to COPD has doubled within the last 30 years and is still increasing, while the rates for the other three top causes of death (heart disease, cancer and stroke) have decreased by over 50 percent. The number of people with asthma in the U.S. has surged over 150 percent since 1980 and the root causes of the disease are still not fully known. Research into the diagnosis, treatment and prevention of lung diseases should be expanded to meet the increasing public health burden of these diseases.

National Institutes of Health

The NIH is the world's leader in groundbreaking biomedical health research into the prevention, treatment and cure of diseases such as lung cancer, COPD and tuberculosis. But due to eroded funding, the success rate for NIH research grants has plummeted to below 13 percent, which means that more than 85 percent of meritorious research is not being funded. The implementation of budget sequestration in fiscal year 2013 will cut NIH by an additional \$1.5 billion, which will result in the elimination of at least 1,000 grant opportunities and cuts of up to 10 percent for continuing grants. These cuts will result in the halting of vital research into diseases affecting millions around the world. We ask the subcommittee to provide \$32 billion in funding for the NIH in fiscal year 2014.

Despite the rising lung disease burden, lung disease research is underfunded. In fiscal year 2012, lung disease research represented just 23.2 percent of the National Heart Lung and Blood Institute's (NHLBI) budget. Although lung disease is the third leading cause of death in the U.S., research funding for the disease is a small fraction of the money invested for the other three leading causes of death. In order to stem the devastating effects of lung disease, research funding must continue to grow.

Centers for Disease Control and Prevention

In order to ensure that health promotion and chronic disease prevention are given top priority in Federal funding, the ATS supports a funding level for the Centers for Disease Control and Prevention (CDC) that enables it to carry out its prevention mission, and ensure a translation of new research into effective State and local public health programs. We ask that the CDC budget be adjusted to reflect increased needs in chronic disease prevention, infectious disease control, including TB control and occupational safety and health research and training. The ATS recommends a funding level of \$7.8 billion for the CDC in fiscal year 2014.

COPD

COPD is the third leading cause of death in the United States and the third leading cause of death worldwide. CDC estimates that 12 million patients have COPD; an additional 12 million Americans are unaware that they have this life threatening disease. In 2010, the estimated economic cost of lung disease in the U.S. was \$186 billion, including \$117 billion in direct health expenditures and \$69 billion in indirect morbidity and mortality costs.

Despite the growing burden of COPD, the U.S. does not have a public health action plan on the disease. The ATS is pleased that the NHLBI is developing a national action plan, in coordination with the Centers for Disease Control and Prevention (CDC) to expand COPD surveillance, develop public health interventions and expand research public awareness of the disease. The NHLBI has shown successful leadership in educating the public about COPD through the COPD Education and Prevention Program.

CDC has an additional role to play in this work. We urge CDC to include COPD-based questions to future CDC health surveys, including the National Health and Nutrition Evaluation Survey (NHANES) and the National Health Information Survey (NHIS).

Tobacco Control

Cigarette smoking is the leading preventable cause of death in the U.S., responsible for one in five deaths annually. The ATS is pleased that the Department of Health and Human Services has made tobacco use prevention a key priority. The CDC's Office of Smoking and Health coordinates public health efforts to reduce tobacco use. In order to significantly reduce tobacco use within 5 years, as recommended by the subcommittee in fiscal year 2010, the ATS recommends a total funding level of \$197 million for the Office of Smoking and Health in fiscal year 2014.

Asthma

Asthma is a significant public health problem in the United States. Approximately 25 million Americans currently have asthma. In 2010, 3,388 Americans died as a result of asthma exacerbations. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease. The disease costs our healthcare system over \$50.1 billion per year. African Americans have the highest asthma prevalence of any racial/ethnic group and the age-adjusted death rate for asthma in this population is three times the rate in whites. One of the keys to reducing asthma exacerbations and the associated healthcare costs is through patient education on asthma management. A study published in the American Journal of Respiratory Critical Care in 2012 found that for every dollar invested in asthma interventions, there was a \$36 benefit. We ask that the subcommittee's appropriations request for fiscal year 2014 that funding for CDC's National Asthma Control Program be maintained at a funding level of at least \$25.3 million and that the National Asthma Control Program remain as a distinct, stand-alone program.

Sleep

Several research studies demonstrate that sleep-disordered breathing and sleep-related illnesses affect an estimated 50–70 million Americans. The public health impact of sleep illnesses and sleep disordered breathing is still being determined, but is known to include increased mortality, traffic accidents, cardiovascular disease, obesity, mental health disorders, and other sleep-related comorbidities. Despite the increased need for study in this area, research on sleep and sleep-related disorders has been underfunded. The ATS recommends a funding level of \$1 million in fiscal year 2014 to support activities related to sleep and sleep disorders at the CDC, including for the National Sleep Awareness Roundtable (NSART), surveillance activities, and public educational activities. The ATS also recommends an increase of funding for research on sleep disorders at the National Center for Sleep Disordered Research (NCSDR) at the NHLBI.

Tuberculosis

Tuberculosis (TB) is the second leading global infectious disease killer, claiming 1.4 million lives each year. In the U.S., every State reports cases of TB annually. Drug-resistant TB poses a particular challenge to domestic TB control due to the high costs of treatment and intensive health care resources required. Treatment costs for multidrug-resistant (MDR) TB range from \$100,000 to \$300,000. The global TB pandemic and spread of drug resistant TB present a persistent public health threat to the U.S.

Despite declining rates, persistent challenges to TB control in the U.S. remain. Specifically: (1) racial and ethnic minorities continue to suffer from TB more than majority populations; (2) foreign-born persons are adversely impacted; (3) sporadic outbreaks occur, outstripping local capacity; (4) drug resistant TB cases are on the rise; and (5) there are critical needs for new diagnostics, treatment and prevention tools.

The Comprehensive Tuberculosis Elimination Act (CTEA, Public Law 110-392), enacted in 2008, reauthorized programs at CDC with the goal of putting the U.S. back on the path to eliminating TB. The ATS, recommends a funding level of \$243 million in fiscal year 2014 for CDC's Division of TB Elimination, as authorized under the CTEA, and encourages the NIH to expand efforts to develop new tools to reduce the rising global TB burden.

Critical Illness

The burden associated with the provision of care to critically ill patients is enormous, and is anticipated to increase significantly as the population ages. Approximately 200,000 people in the United States require hospitalization in an intensive care unit because they develop a form of pulmonary disease called Acute Lung Injury. Despite the best available treatments, 75,000 of these individuals die each year from this disease. This is the approximately the same number of deaths each year due to breast cancer, colon cancer, and prostate cancer combined. Investigation into diagnosis, treatment and outcomes in critically ill patients should be a priority, and the NIH should be encouraged and funded to coordinate investigation in this area in order to meet this growing national imperative.

Pediatric Lung Disease

The ATS is pleased to report that infant death rates for various lung diseases have declined for the past 10 years. In 2009, of the 10 leading causes of infant mortality, 4 were lung diseases or had a lung disease component. Many of the precursors of adult respiratory disease start in childhood. Many children with respiratory illness grow into adults with COPD. It is estimated that 7.1 million children suffer from asthma. While some children appear to outgrow their asthma when they reach adulthood, 75 percent will require life-long treatment and monitoring of their condition. The ATS encourages the NHLBI to continue with its research efforts to study lung development and pediatric lung diseases.

Fogarty International Center

The Fogarty International Center (FIC) provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health professionals in TB treatment and research. The ATS recommends Congress provide \$72.8 million for FIC in fiscal year 2014, to allow expansion of the TB training grant program from a supplemental grant to an open competition grant.

Researching and Preventing Occupational Lung Disease

The ATS urges the subcommittee to provide at least level funding for the National Institute for Occupational Safety and Health (NIOSH). NIOSH, within the Centers for Disease Control and Prevention (CDC), is the primary Federal agency responsible for conducting research and making recommendations for the prevention of work-related illness and injury. NIOSH provides national and world leadership to avert workplace illness, injury, disability, and death by gathering information, conducting scientific research, and translating this knowledge into products and services. NIOSH supports programs in every State to improve the health and safety of workers.

The ATS appreciates the opportunity to submit this statement to the subcommittee.

PREPARED STATEMENT OF THE AMERICANS FOR NURSING SHORTAGE RELIEF (ANSR)

The organizations of the ANSR Alliance greatly appreciate the opportunity to submit written testimony recommending \$251 million for the Title VIII Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) and \$20 million for the Nurse Managed Health Clinics as authorized under Title III of the Public Health Service Act. We represent a diverse cross-section of health care and other related organizations, health care providers, and supporters of nursing issues (<http://www.ansralliance.org/Members.html>) that have united to address the national nursing shortage. ANSR stands ready to work with Congress

to advance programs and policy that will ensure our Nation has a sufficient and adequately prepared nursing workforce to provide quality care to all well into the 21st century.

The Nursing Shortage

Nursing is the largest health care profession in the United States. Nurses work in a variety of settings, including primary care, public health, long-term care, surgical care facilities, schools, and hospitals. The March 2008 study, *The Future of the Nursing Workforce in the United States: Data, Trends, and Implications*, calculates a projected demand of 500,000 full-time equivalent registered nurses by 2025. According to the U.S. Bureau of Labor Statistics, due to the country's gaining population and increasing health needs, employment of registered nurses is expected to grow by 26 percent from 2010 to 2020 resulting in 711,900 new jobs. The Title VIII Nursing Workforce Education Programs will help fill these vacancies by supporting training programs designed to meet these health care needs.

The Title VIII Nursing Workforce and Education programs provide training for entry-level and advanced degree nurses to improve the access to, and the quality of, health care in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2005 and 2010, supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions and health care facilities.

The Desperate Need for Nurse Faculty

Nursing vacancies exist throughout the entire health care system, including long-term care, home care and public health. Government estimates indicate that this situation only promises to worsen due to an insufficient supply of individuals matriculating in nursing schools, an aging existing workforce, and the inadequate availability of nursing faculty to educate and train the next generation of nurses. At the exact same time that the nursing shortage is expected to worsen, the baby boom generation is aging and the number of individuals with serious, life-threatening, and chronic conditions requiring nursing care will increase.

Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. Securing and retaining adequate numbers of faculty is essential to ensure that all individuals interested in—and qualified for—nursing school can matriculate in the year that they are accepted.

ANSR supports the need for sustained attention on the efficacy and performance of existing and proposed programs to improve nursing practices and strengthen the nursing workforce. The support of research and evaluation studies that test models of nursing practice and workforce development is integral to advancing health care for all in America. Investments in research and evaluation studies have a direct effect on the caliber of nursing care. Our collective goal of improving the quality of patient care, reducing costs, and efficiently delivering appropriate health care to those in need is served best by aggressive nursing research and performance and impact evaluation at the program level.

The Nursing Supply Impacts the Nation's Health and Economic Safety

The demand for primary care services in the U.S. is expected to increase over the next few years, particularly with the aging and growth of the population. One study projects that by the year 2019, the demand for primary care in the United States will increase by between 15 million and 25 million visits per year. HRSA estimates that more than 35.2 million people living within the 5,870 Health Professional Shortage Areas nationwide do not currently receive adequate primary care services. Research suggests that nurses and other health professionals are trained to and already do deliver many primary care services and may therefore be able to help increase access to primary care, particularly in underserved areas.

ANSR applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce. For nearly 50 years, the Title VIII Nursing Workforce Development Programs have responded to the Nation's evolving workforce needs by providing education and training opportunities to nurses. These programs are the only Federal programs focused on filling gaps in the supply of nurses not met by traditional market forces, as well as producing a workforce prepared to care for the Nation's increasingly diverse and aging population. Numerous studies have demonstrated that the Title VIII programs graduate more minority and disadvantaged students more likely to serve in community health centers as well as rural and underserved areas. In a difficult economy, the Title VIII Nursing Workforce Education Programs help schools offer

scholarships and affordable loans to nursing students, making such educational opportunities available to aspiring nurses of all backgrounds. By guiding job seekers to high-demand nursing jobs, the programs fulfill both their individual career goals and a community's health needs.

Summary

HRSA's Title VIII Nursing Workforce Education programs contribute to a sufficient nursing workforce to meet the demands of a highly diverse and aging population is an essential component to improving the health status of the Nation and reducing health care costs. While the ANSR Alliance understands the immense fiscal pressures facing the Nation, we respectfully urge support for \$251 million in funding for Nursing Workforce Development Programs under Title VIII of the Public Health Service Act at HRSA and \$20 million for the Nurse Managed Health Clinics under Title III of the Public Health Service Act in fiscal year 2013. We look forward to working with the subcommittee to prioritize the Title VIII programs in fiscal year 2014 and the future.

LIST OF ANSR MEMBER ORGANIZATIONS

Academy of Medical-Surgical Nurses	National Association of Clinical Nurse Specialists
American Academy of Ambulatory Care Nursing	National Association of Hispanic Nurses
American Academy of Nurse Practitioners	National Association of Neonatal Nurses
American Academy of Nursing	National Association of Neonatal Nurse Practitioners
American Association of Nurse Anesthetists	National Association of Nurse Massage Therapists
American Association of Nurse Assessment Coordination	National Association of Nurse Practitioners in Women's Health
American Association of Occupational Health Nurses	National Association of Orthopedic Nurses
American College of Nurse-Midwives	National Association of Registered Nurse First Assistants
American Organization of Nurse Executives	National Association of School Nurses
American Psychiatric Nurses Association	National Black Nurses Association
American Society for Pain Management Nursing	National Council of State Boards of Nursing
American Society of PeriAnesthesia Nurses	National Council of Women's Organizations
American Society of Plastic Surgical Nurses	National Gerontological Nursing Association
Association for Radiologic & Imaging Nursing	National League for Nursing
Association of Pediatric Hematology/Oncology Nurses	National Nursing Centers Consortium
Association of State and Territorial Directors of Nursing	National Nursing Staff Development Organization
Association of Women's Health, Obstetric & Neonatal Nurses	National Organization for Associate Degree Nursing
Citizen Advocacy Center	National Student Nurses' Association, Inc.
Dermatology Nurses' Association	Nurses Organization of Veterans Affairs
Developmental Disabilities Nurses Association	Pediatric Endocrinology Nursing Society
Emergency Nurses Association	Preventive Cardiovascular Nurses Association
Infusion Nurses Society	RN First Assistants Policy & Advocacy Coalition
International Association of Forensic Nurses	Society of Gastroenterology Nurses and Associates, Inc.
International Nurses Society on Addictions	Society of Pediatric Nurses
International Society of Nurses in Genetics, Inc.	Society of Trauma Nurses
Legislative Coalition of Virginia Nurses	Women's Research & Education Institute
	Wound, Ostomy and Continence Nurses Society

PREPARED STATEMENT OF THE ARTHRITIS FOUNDATION

SUMMARY REQUEST

National Institutes of Health overall funding	\$32,000,000,000
NIH: National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)	525,000,000
Health Resources and Services Administration Pediatric Subspecialty Loan Repayment Program	5,000,000
Centers for Disease Control CDC Arthritis Program	15,000,000

The Arthritis Foundation is committed to raising awareness and reducing the unacceptable impact of arthritis, which strikes one in every five adults and 300,000 children, and is the Nation's leading cause of disability. The Arthritis Foundation would like to provide recommendations for the Labor Health and Human Services (Labor HHS) Budget for fiscal year 2014.

Specifically, we would like to comment on three specific agencies of jurisdiction of the Labor HHS Appropriations Subcommittee: the National Institutes of Health (NIH) and in particular the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the Health Services Resources Administration (HRSA) and the Centers for Disease Control (CDC).

ARTHRITIS RELATED RESEARCH INVESTMENTS AT THE NATIONAL INSTITUTES OF HEALTH (NIH): FUNDING FOR THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES (NIAMS)

Research holds the key to preventing, controlling, and curing arthritis, the Nation's leading cause of disability. The prevalence, impact and disabling pain continues to increase. 50 million Americans—one in five adults—have arthritis now. Within 20 years, the Centers for Disease Control and Prevention (CDC) estimates that 67 million adults or 25 percent of the population will have arthritis. Arthritis limits the daily activities of 21 million Americans and accounts for \$128 billion annually in economic costs. The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) supports research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases. The critical research done at NIAMS improves the quality of life for people with arthritis and decreases the overall burden of the disease. NIH funding should be allocated \$32 billion for fiscal year 2014 and NIAMS should be funded at \$559 million to fund critical research on arthritis and other related diseases at the Institute. Our NIH recommendations reflect , the minimum needed to sustain the current level of research and account for inflation.

HRSA PEDIATRIC SUBSPECIALTY LOAN REPAYMENT PROGRAM

Juvenile arthritis is one of the most common childhood diseases, affecting more children than cystic fibrosis and muscular dystrophy. Currently, there are less than 250 board-certified practicing pediatric rheumatologists in the United States and about 90 percent of those are clustered in and around large cities. Pediatric rheumatology has one of the smallest numbers of doctors of any pediatric subspecialty. Of those children with juvenile arthritis, only one-fourth see a pediatric rheumatologist due to their scarcity. The other 75 percent of juvenile arthritis patients see either pediatricians (who tend not to be trained in how to care for juvenile arthritis) or adult rheumatologists, who aren't trained to deal with pediatric issues. Issues such as whether it's the stunted bone growth that can result from arthritis and its treatment, or the unwillingness of an adolescent to take his medicine. There are currently eleven States that do not have a single practicing, board-certified pediatric rheumatologist and seven States with only one practicing board-certified pediatric rheumatologist.

The Pediatric Subspecialty Loan Repayment Program was authorized by Section 5203 of the Affordable Care Act (ACA) in March 2010. The program would incentivize training and practice in pediatric medical subspecialties, like pediatric rheumatology, in underserved areas across the United States. The program would offer up to \$35,000 in loan forgiveness for each year of service for a maximum of 3 years. The program was authorized for \$30 million for fiscal year 2010 through fiscal year 2014, but has yet to be appropriated any funding. President Obama's fiscal year 2014 budget requests \$5 million to fund the Pediatric Subspecialty Loan Repayment Program. The Arthritis Foundation urges Congress to allocate \$5 million dollars to fund the Pediatric Subspecialty Loan Repayment Program.

CENTER FOR DISEASE CONTROL: CDC ARTHRITIS PROGRAM

The goal of the CDC Arthritis Program is to improve the quality of life for people affected by arthritis and other rheumatic conditions by working with States and other partners to (1) increase awareness about appropriate arthritis self-management activities; (2) expanding the reach of programs proven to improve the quality of life for people with arthritis and (3) decrease the overall burden of arthritis as well as its associated disability, work and activity limitations.

The Arthritis Foundation requests that Congress provide a slight increase (\$2 million) to expand the CDC Arthritis Program to \$15 million for fiscal year 2014. These additional funds would allow the Program to expand to two additional States. These State-based programs would (1) increase evidence based interventions, such as the Arthritis Foundation's Walk with Ease Program (WWE), into more communities; (2) reach diverse populations by funding partnership activities; and (3) support the OA Action Alliance, a coalition committed to elevating OA as a national priority. www.oaactionalliance.org.

The Arthritis Foundation appreciates the opportunity to provide recommendations to the Senate Labor Health and Human Services Committee on recommendations for fiscal year 2014.

If you have questions about these comments, please don't hesitate to contact the Arthritis Foundation. Questions about HRSA request—Kim Beer, Director, Advocacy, kbeer@arthritis.org or Maria Spencer, Director, Federal Affairs for NIH/CDC, msspencer@arthritis.org.

PREPARED STATEMENT OF THE ASSOCIATION FOR RESEARCH IN VISION AND
OPHTHALMOLOGY (ARVO)

EXECUTIVE SUMMARY

ARVO is a community of more than 12,750 vision and ophthalmology researchers from 80 countries; we are the largest, most respected eye and vision research organization in the world. Our aim is to help cure and prevent blindness by encouraging and assisting research, training, publication and knowledge-sharing. In that regard, ARVO is pleased to make the following request regarding fiscal year 2014 appropriations:

Congress fund the National Institutes of Health (NIH) at \$32 billion, which reflects a \$1.38 billion, or 4.5 percent increase, over fiscal year 2012, which consists of biomedical inflation of 2.8 percent plus modest growth.

—This recommendation reflects the minimum investment necessary to make up for the 20 percent loss in purchasing power over the last decade, as well as the impact of the sequester, which cut 5.1 percent or \$1.6 billion from NIH's \$30.8 billion budget.

—NIH funding, especially in basic research, plays an essential role that the private sector could not duplicate.

Congress fund the National Eye Institute (NEI) at \$730 million within the overall NIH funding increase. The President's budget proposes a fiscal year 2014 NEI funding cut of \$2.1 million to a level \$699 million, which is unacceptable because:

—It cuts 35 competing grants. The \$36 million cut in fiscal year 2013 NEI funding due to the sequester has already translated into a loss of an estimated 90 grants—any one of which holds the promise to save or restore vision.

—The cut jeopardizes NEI's ability to fund new and compelling scientific ideas to advance research, which were identified through its Audacious Goals Initiative.

In fiscal year 2012 and fiscal year 2013 funding, with the latter including the sequester, the vision research community has experienced the "perfect storm"—cuts to new grants, no inflationary increases to existing grants, which may also be cut, and the reduction of the salary cap from Executive Level (EL) I to EL II—which, in totality, threaten the development of the next generation of vision scientists and the United States' leadership in vision research. Every researcher within our community has been impacted—seasoned researchers, new and young investigators, students-in-training, and clinician scientists—and each institution has been affected in terms of its ability to retain and attract trained personnel and to balance Federal funding cuts with bridge or philanthropic funding in an effort to maintain the momentum of past research.

As a result, ARVO asks Congress to carefully consider every aspect of fiscal year 2014 NIH and NEI appropriations—the funding level, the impact on new and existing grants, and the salary cap, the past reduction of which to EL II has disproportionately affected clinician-scientists who are critical to the translation of basic science. ARVO also asks Congress to fully consider the consequences for the current

and future generation of scientists who are not only helping to understand the basis of disease, but developing treatments and therapies to save and restore vision as well as improve lives .

ARVO REQUESTS THAT CONGRESS IMPROVE UPON THE PRESIDENT'S FISCAL YEAR 2014 REQUEST, WHICH CUTS NEI FUNDING AND THREATENS RESEARCH

Despite the President's request increasing NIH funding by \$471 million, or 1.5 percent, over the fiscal year 2012 level of \$30.6 billion (net of transfers), it proposes to cut NEI by \$2.1 million, or 0.3 percent, below its fiscal year 2012 level of \$701.3 million (net of transfers). Although the cut is primarily driven by an \$8.9 million reduction due to the conclusion of the NEI-sponsored Ocular Complications of AIDS (SOCA) studies, which are funded by the NIH Office of AIDS Research, it is still a cut and drives NEI funding in the wrong direction. The President's proposed fiscal year 2014 NEI funding level of \$699 million falls \$8 million below the base fiscal year 2010 level of \$707 million, the highest NEI funding level ever prior to the addition of American Recovery and Reinvestment Act (ARRA) funding.

Most importantly, the President's proposed fiscal year 2014 NEI cut of \$2.1 million comes after the fiscal year 2013 sequester cut of \$36 million. The President's fiscal year 2014 budget would cut 35 competing grants from NEI funding, which follows a \$36 million reduction in NEI funding due to the sequester in fiscal year 2013 that has already translated into a loss of an estimated 90 grants—any one of which holds the promise of sight.

The very health of the vision research community is at stake with a decrease in NEI funding. Not only will funding for new investigators and those in training be at risk, but also that of seasoned investigators, which threatens the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding. If an institution needs to let staff go, that could result in a highly-trained person leaving research altogether or moving to an institution in another country.

This threatens the United States' leadership in vision research. Despite efforts in many ARVO members' home countries to increase medical and vision research funding, especially in China and India, they readily acknowledge that NEI-funded research still leads the world's efforts to save and restore vision. Since many of these members have also received their training in the U.S., they also value the importance of ongoing collaborations with U.S.-based investigators. NEI's leadership is essential to a global synergy that is resulting in the breakthroughs in vision research.

ARVO also requests NEI funding at \$730 million since our Nation's investment in vision health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of life, especially since vision loss is associated with increased depression and accelerated mortality.

ARVO REQUESTS FISCAL YEAR 2014 NEI FUNDING AT \$730 MILLION TO ENABLE IT TO BUILD UPON ITS PAST RECORD OF BASIC AND TRANSLATIONAL RESEARCH AND PURSUE THE MOST AUDACIOUS GOALS IN VISION RESEARCH

The NEI is in the middle of a novel planning initiative to identify long-term, ten-year goals in vision research. Under the auspices of the National Advisory Eye Council, this expansion of NEI program planning is designed to engage and energize the vision research community and help the NEI establish the most compelling research priorities by identifying one or more "audacious goals." Most recently, NEI hosted 200 representatives from every sector of the vision community, as well as Government scientists and regulators from various disciplines at the NEI's Audacious Goals Development meeting. NIH Director Francis Collins, M.D., Ph.D. was very enthusiastic about this initiative and urged the attendees to have a "bold vision for vision" by describing NEI's long tradition of leadership in the biomedical research arena, including:

- identifying more than 500 genes associated with vision loss, which is one-quarter of all genes discovered to date; and
- funding the successful human gene therapy trial for patients with Leber Congenital Amaurosis, in which treated patients have experienced vision improvement.

The meeting's discussion topics were built around the 10 winning submissions from a pool of nearly 500 entries selected through NEI's Audacious Goals in Vision Research and Blindness Rehabilitation Challenge, a competition for bold and novel

ideas to dramatically advance vision science. These ideas included restoring light sensitivity to the blind through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants. Translating these and other research ideas into safe and effective treatments to save and restore vision requires adequate funding.

NEI has always envisioned the future. Just a few short years ago, the “bionic eye” was just a fantasy. However, In February 2013, the Food and Drug Administration (FDA) approved an implanted retinal prosthesis to treat adult patients with advanced retinitis pigmentosa (RP), a rare genetic condition that damages the retina and leads to blindness. In this device, developed in part with NEI funding, a small video camera mounted on a pair of glasses sends images to a video processing unit that converts them to electronic data that is wirelessly transmitted to an array of electrodes implanted onto the retina. The device is enabling those who are otherwise completely blind to identify doors, crosswalks, and even utensils on a table. Funding must be adequate for NEI to successfully pursue its goal of saving and restoring vision.

BLINDNESS AND VISION LOSS IS A GROWING PUBLIC HEALTH PROBLEM THAT
INDIVIDUALS FEAR AND WOULD TRADE YEARS OF LIFE TO AVOID

NEI is already facing enormous challenges this decade: each day, from 2011 to 2029, 10,000 citizens will turn 65 and be at greatest risk for eye disease; the fast growing African American and Hispanic populations will experience a disproportionately higher incidence of eye disease; and the epidemic of obesity will significantly increase the incidence of diabetic retinopathy.

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as age-related macular degeneration (AMD), glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by the year 2020. Although NEI estimates that the current annual cost of vision impairment and eye disease to the U.S. is \$68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI’s proposed fiscal year 2014 funding of \$699 million reflects just a little more than 1 percent of this annual costs of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to the public and private sectors.

Vision loss also presents a real fear to most citizens. In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. NEI’s Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a “10” on a scale of 1 to 10, meaning that it would have the greatest impact on their day-to-day life. In patients with diabetes, going blind or experiencing vision loss rank among the top four concerns about the disease. These patients are so concerned about vision loss diminishing their quality of life that those with nearly perfect vision (20/20 to 20/25) would be willing to trade 15 percent of their remaining life for “perfect vision,” while those with moderate impairment (20/30 to 20/100) would be willing to trade 22 percent of their remaining life for perfect vision. Patients who are legally blind from diabetes (20/200 to 20/400) would be willing to trade 36 percent of their remaining life to regain perfect vision.

ARVO urges Congress to fund NIH at \$32 billion and NEI at \$730 million, in fiscal year 2014 to ensure the momentum of research, to retain trained personnel, and maintain U.S. leadership.

PREPARED STATEMENT OF THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY AND THE SOCIETY FOR HEALTHCARE EPIDEMIOLOGY OF AMERICA

The Association for Professionals in Infection Control and Epidemiology (APIC) and the Society for Healthcare Epidemiology of America (SHEA) thank you for this opportunity to submit testimony on Federal efforts to detect dangerous infectious diseases and protect the American public from healthcare-associated infections (HAIs). We ask that the subcommittee support the following programs under appropriations for the Department of Health and Human Services.

First, under the Centers for Disease Control and Prevention National Center for Emerging and Zoonotic Infectious Diseases: \$31.5 million for the National Healthcare Safety Network (NHSN) and the Prevention Epicenters Program; \$40 million for the Advanced Molecular Detection and Response to Infectious Disease

Outbreaks Program; and \$226.7 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antimicrobial Resistance, and the Emerging Infections Program (EIP). Additionally, we request \$34 million for the Agency for Healthcare Research and Quality (AHRQ) to reduce and prevent HAIs. This includes \$12.6 million in HAI research grants and \$21.4 million in HAI contracts including the Comprehensive Unit-based Safety Program (CUSP). These CDC requests include the agency's recommendations related to the Working Capital Fund. Finally, we request \$500 million annually for the National Institutes of Health (NIH), National Institute of Allergy and Infectious Diseases' antibacterial and related diagnostics efforts by the end of fiscal year 2014.

HAIs are among the leading causes of preventable death in the United States. In hospitals alone, CDC estimates that one in 20 hospitalized patients has an HAI, while over one million HAIs occur across healthcare settings annually.

In addition to the substantial human suffering, HAIs contribute \$28 to \$33 billion in excess healthcare costs each year. Fortunately several HAIs are on the decline as a result of recent advances in the understanding of how to prevent certain infections. In particular, bloodstream infections associated with indwelling central venous catheters, or "central lines," are largely preventable when healthcare providers use the CDC infection prevention recommendations in the context of a performance improvement collaborative. CDC recently reported a 41 percent reduction in central line-associated bloodstream infections in 2011. The reduction in central line associated bloodstream infections over the last 4 years has saved 5,000 lives and averted an estimated \$83 million in healthcare costs. Now we have the opportunity to continue this momentum and extend it to other infections.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

APIC and SHEA request \$31.5 million for the National Healthcare Safety Network (NHSN) and the Prevention Epicenters Program. These programs provide critical funding to detect dangerous multidrug-resistant organisms (MDROs) in order to protect patients and the public from disease and death associated with HAIs.

APIC and SHEA are strongly supportive of the Prevention Epicenters Program, a collaboration of CDC's Division of Healthcare Quality Promotion (DHQP) and academic medical centers that conduct innovative infection control and prevention research to address important scientific gaps regarding the prevention of HAIs, antibiotic resistance and other adverse healthcare events.

Consistent, high quality, scientifically sound and validated data are necessary to measure the true extent of the problem, develop evidence-based HAI prevention strategies, and to ensure that accurate data are available at the State and Federal level for public reporting.

Funding for this program has been flat since fiscal year 2010, despite the system's importance in our Nation's efforts to monitor and prevent HAIs, and the increase in facilities reporting into the NHSN—from 3,000 in 2010 to nearly 12,000 in 2013.

APIC and SHEA request \$226.7 million for Core Infectious Diseases to include funding for Healthcare-Associated Infections, Antimicrobial Resistance, and Emerging Infections Program.

APIC and SHEA support the EIP as it helps States, localities and territories in detecting and protecting the public from known infectious disease threats in their communities while maintaining our Nation's capacity to identify new threats as they emerge.

Further, ensuring the effectiveness of antibiotics well into the future is vital for the Nation's public health, particularly when our current therapeutic options are now dwindling and research and development of new antibiotics is lagging. As noted in the recently released CDC Vital Signs report related to carbapenem-resistant Enterobacteriaceae (CRE), microorganisms are becoming more resistant to antimicrobials. Such resistance is one of the most pressing challenges facing healthcare providers and patients in the coming decade, so it is essential that the CDC maintain the ability to monitor organism resistance.

APIC and SHEA request \$40 million for the Advanced Molecular Detection and Response to Infectious Disease Outbreaks Program (AMD). This program will improve urgently needed molecular and bioinformatics capacities for controlling infectious disease threats at the national and State level.

Modernizing public health microbiology capacities through the AMD program will ensure CDC is able to meet its basic public health mission by keeping pace with major technologic advances in the diagnosis and characterization of infectious agents and reducing the burden of infectious diseases. AMD will allow for the efficient determination of the origin of emerging diseases, whether microorganisms are

resistant to antimicrobials, and how microorganisms maneuver and alter through a population.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

APIC and SHEA request \$34 million for AHRQ in fiscal year 2014 to reduce and prevent HAIs. This total includes funding for HAI research grants to improve the prevention and management of HAIs, and HAI contracts including nationwide implementation of the Comprehensive Unit-based Safety Program (CUSP). Over the past decade, AHRQ has funded numerous projects targeting HAI prevention that have led to the successful reduction of central line-associated bloodstream infections (CLABSIs) in hospital intensive care units (ICUs) by 58 percent since 2001, representing up to 27,000 lives saved. In spite of this notable progress, there is a great deal of work to be done toward the goal of HAI elimination. SHEA and APIC are very pleased that AHRQ is expanding the CUSP program to reach healthcare settings outside the ICU and to broaden the focus to address other types of infection.

NATIONAL INSTITUTES OF HEALTH (NIH), NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID)

APIC and SHEA request that at least \$500 million annually be provided for NIAID's antibacterial and related diagnostics efforts by the end of fiscal year 2014. As part of this effort, we believe NIAID should invest at least \$100 million per year in the antibiotic resistance-focused clinical trials network that the Institute is currently establishing and should be operational by 2014. Although we applaud NIAID for establishing this new network, we believe the planned investment of \$10 million per year over the next 10 years will be insufficient to undertake the critical studies needed to address what are quickly becoming untreatable infections. We thank you for the opportunity to submit testimony and greatly appreciate this subcommittee's assistance in providing the necessary funding for the Federal Government to have a leadership role in the effort to eliminate HAIs.

About APIC.—APIC's mission is dedicated to creating a safer world through prevention of infection. The association's more than 14,000 members direct and maintain infection prevention programs that prevent suffering, save lives and contribute to cost savings for hospitals and other healthcare facilities. APIC advances its mission through patient safety, implementation science, competencies and certification, advocacy, and data standardization.

About SHEA.—Founded in 1980, SHEA works to achieve the highest quality of patient care and healthcare personnel safety in all healthcare settings by applying epidemiologic principles and prevention strategies to a wide range of quality-of-care issues. SHEA's membership of 2,000 represents all branches of medicine, public health, and healthcare epidemiology. SHEA members are committed to implementing evidence-based strategies to prevent HAIs and improve patient safety, and have scientific expertise in evaluating potential strategies to accomplish this goal.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN CANCER INSTITUTES

The Association of American Cancer Institutes (AACI), representing 95 of the Nation's premier academic and free-standing cancer centers, appreciates the opportunity to submit this statement for consideration by the United States Senate's Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations.

AACI thanks the President, Congress and the subcommittee for its long-standing commitment to ensuring quality care for cancer patients, as well as for providing researchers with the resources that they need to develop better cancer treatments and, ultimately, to cure this disease.

The President's fiscal year 2014 budget requests \$31.3 billion for the National Institutes of Health (NIH), an increase of \$471 million (1.5 percent) over the fiscal year 2012 level. This amount includes \$5.125 billion for the National Cancer Institute (NCI), a \$63 million increase over fiscal year 2012 (1.2 percent). However, the President's budget request does not account for the cuts due to sequestration. Unless Congress acts to replace the sequester, the automatic spending cuts will reduce the NIH and NCI budgets further through 2021.

AACI joins with our colleagues in the biomedical research community in recommending that the subcommittee recognize NIH as a critical national priority by providing at least \$32 billion in funding in the fiscal year 2014 Labor-HHS-Education Appropriations bill, including an equivalent percentage increase in funding for NCI.

This funding level represents the minimum investment necessary to avoid further loss of promising research.

AACI cancer centers are at the front line in the national effort to eradicate cancer. The cancer centers that AACI represents house more than 20,000 scientific, clinical and public health investigators who work collaboratively to translate promising research findings into new approaches to prevent and treat cancer. Making progress against cancer is complex as it takes a significant amount of time to discovery new therapies and treatments for cancer patients. However, the pace of discovery and translation of novel basic research to new therapies could be faster if researchers could count on an appropriate and predictable investment in Federal cancer funding. Cuts to the NIH budget have a real impact on progress against cancer at cancer centers across the country. Continued progress in cancer research is dependent on the sustained efforts of highly skilled research teams working at cancer centers across the country and supported by the NCI. Failure to keep up with the rate of biomedical inflation diminishes many of the research teams working on new treatments and new cures.

AACI and its members are profoundly aware of the country's fiscal environment. The vast majority of our cancer centers exist within universities that are absorbing severe budget reductions. Furthermore, because of the reduced funding pool for meritorious grant applications, many of our senior and most promising young investigators are now without NCI funding and require significant bridge funding from private sources. In recent years, however, it has become more challenging to raise philanthropic and other external funds. As a result, we continue to be highly dependent on Federal cancer center grants. The lack of funding for promising young scientists risks driving an entire generation of young cancer physicians and researchers either abroad, to seek opportunities to practice their craft and advance their careers, or out of the field altogether. These serious consequences for biomedical jobs and local economies mean that funding cuts will undermine U.S. competitiveness, at a time when other nations are aggressively boosting their investments in research and development.

Impact in the Lab and Beyond

The negative effects of diminished biomedical research funding reach beyond the lab and into local communities, as chronicled by a number of AACI cancer center directors who were featured in newspaper editorials or interviews that highlighted the impact of NIH and NCI funding on people and local economies in their individual States.

For example, AACI President Michelle M. Le Beau, PhD, director of the University of Chicago Comprehensive Cancer Center and AACI Vice-President/President-Elect George Weiner, MD, director of the Holden Comprehensive Cancer Center at the University of Iowa noted that at their respective NCI-designated Comprehensive Cancer Centers alone, sequestration has begun to undermine innovative work being done to harness a patient's own immune system to fight cancer, genomic profiling of patients' cancers to personalize treatment, and the evaluation of more sensitive imaging technology for early detection of cancer.

Nancy E. Davidson, MD, director of the University of Pittsburgh Cancer Institute, told a local newspaper that she has serious concerns about the cuts, which she said would affect the institute's work. She noted that budget cuts would force her to eliminate jobs, shut laboratories and halt promising experiments. She stated that she would not be able to hire faculty members and faces the possibility of shutting down programs.

Roy A. Jensen, MD, director of the University of Kansas Cancer Center said, "It's really come on top of a fairly extended period of flat funding, which has eroded the purchasing power of biomedical dollars. . . It's almost like the final push over the edge. I know a lot of labs are having to lay people off and not pursuing promising scientific leads."

Edward J. Benz, Jr., MD, director of the Dana-Farber Cancer Institute, affiliated with Harvard Medical School, stated, "The cuts in Federal funding as they're being put into play are unraveling one of the greatest biomedical-research enterprises in the history of the world. . . These kinds of draconian, across-the-board cuts are really cutting into the meat of what we do."

Ralph de Vere White, MD, director of the UC Davis Comprehensive Cancer Center and associate dean for cancer programs at the UC Davis School of Medicine, wrote in an opinion piece that, "Deterioration of the (funding) pipeline comes at a critical time. Although death rates from most types of cancer have fallen because we are finding and treating tumors earlier, advanced cancers have proved much more challenging. This Nation's investment in cancer research has allowed us to develop the tools to drastically cut that death rate. These tools are not simply costly

new drugs. They are methods to interrogate tumors at the molecular level. They are tests to identify a tumor's genetic characteristics so we can choose appropriate treatments on a patient-by-patient basis so we can spare patients therapies that cause side effects but offer no benefit."

Donald L. Trump, MD, President and CEO of Roswell Park Cancer Institute, in Buffalo, informed his colleagues that proposals within the institute, specifically a proposal for a study on the role specific genes play in metastasis of prostate cancer, the second leading cause of cancer death in American men, will suffer due to budget constraints. Roswell Park anticipated cutting three researchers from this effort—a 33 percent workforce reduction.

Walter J. Curran, Jr., MD, FACR, executive director of Winship Cancer Institute of Emory University, in Atlanta, testified on behalf of AACI before the Committee on Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. He noted that Winship has an outstanding research team making real progress understanding how to target newly discovered mutations causing lung cancer, the type of cancer causing the most deaths in our country. Winship has observed an increase in the number of lung cancer patients who have little or no tobacco use history, and are just beginning to understand the genetic and genomic risk factors of such individuals for developing lung cancer, he said. Dr. Curran was adamant that any cut in funding support of this and other projects could delay finding new and effective therapies for thousands of patients by years.

Recent studies have also concluded that Federal support for medical research is a major determinant in the economic health of communities across the country. In one report, United for Medical Research, a coalition of leading research institutions, patient and health advocates and private industry, estimated that NIH funding generated the greatest number of jobs in California (59,363), Massachusetts (34,031), New York (32,249), Texas (25,408) and North Carolina (18,779) and also supported more than 10,000 jobs each in Pennsylvania, Maryland, Washington, Illinois, Ohio, Florida, Michigan and Georgia. Fifty-five AACI cancer centers are located in those 13 States.

Cancer centers are already challenged to provide infrastructure resources necessary to support funded researchers, and cuts in Federal cancer center grants will limit our members' ability to provide well-functioning shared resources to investigators who depend on them to complete their research. For most academic cancer centers, the majority of NCI grant funds are used to sustain shared resources that are essential to basic, translational, clinical and population cancer research, or to provide matching dollars which allow departments to recruit new cancer researchers to a university and support them until they receive their first grants.

Independent investigator research is a particularly valuable resource, especially in genomics and molecular epidemiology. Such research depends on state-of-the-art shared resources like tissue processing and banking, DNA sequencing, microRNA platforms, proteomics, biostatistics and biomedical informatics. This infrastructure is expensive and it is not clear where cancer centers would acquire alternative funding if NCI grants for these efforts were reduced.

Cancer Research is Improving America's Health

The broad portfolio of research supported by NIH and NCI is essential for improving our basic understanding of diseases and it has paid off considerably in terms of improving Americans' health.

The 5-year relative survival rate for all cancers diagnosed between 2002 and 2008 is 68 percent, up from 49 percent in 1975–1977. The improvement in survival reflects both progress in diagnosing certain cancers at an earlier stage and improvements in treatment. Data has shown specifically that cancer death rates have dropped 11.4 percent among women and 19.2 percent among men over the past 15 years, due in large part to better detection and more effective treatments.¹

Despite that success, cancer remains the second leading cause of death in the U.S., with almost 1,600 deaths per day. More than 1.6 million Americans are expected to be diagnosed with cancer in 2013, with an expected 580,350 people to die from the disease.² NCI estimates that 41 percent of individuals born today will receive a cancer diagnosis at some point in their lifetime.³

The network of cancer centers represented by AACI continues the fight against cancer by conducting the highest-quality cancer research in the world and provides

¹American Cancer Society. Facts and Figures, 2013. <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-036845.pdf>.

²American Cancer Society. Facts and Figures, 2013.

³*Cancer Trends Progress Report—2011/2012 Update*, National Cancer Institute, NIH, DHHS, Bethesda, MD, August 2012, <http://progressreport.cancer.gov>.

exceptional patient care. In 2012, 86 percent of NCI's total budget was awarded extramurally to research institutions, including the AACI's member cancer centers.⁴ Because these centers are networked nationally, opportunities for collaborations are many—assuring wise and non-duplicative investment of scarce Federal dollars.

Conclusion

NIH estimates that the overall costs of cancer in 2008 were \$201.5 billion: \$77.4 billion for direct medical costs (total of all health expenditures) and \$124.0 billion for indirect mortality costs (cost of lost productivity due to premature death).⁵ The cost of cancer continues to rise, but the investment in cancer research will one day eliminate such economic burdens on Americans and the cancer center researchers who work tirelessly to find a cure for this deadly disease.

In the face of that economic burden, the Nation's financial support of NIH and NCI has paid dividends by introducing innovative therapies for cancers that years ago robbed countless Americans of their future. NIH's full support of NCI-designated centers and their programs remains a top priority for our Nation's cancer centers. We are on a clear path to dramatic breakthroughs at cancer centers across the country. It is through the power of collaborative innovation that we will continue to move toward a future without cancer, and Federal research funding is essential to achieving our goals.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

The Association of American Medical Colleges (AAMC) is a not-for-profit association representing all 141 accredited U.S. and 17 accredited Canadian medical schools; nearly 400 major teaching hospitals and health systems; and nearly 90 academic and scientific societies. Through these institutions and organizations, the AAMC represents 128,000 faculty members, 75,000 medical students, and 110,000 resident physicians. The association wishes to address four Federal priorities that play essential roles in assisting medical schools and teaching hospitals to fulfill their missions of education, research, and patient care: the National Institutes of Health (NIH); the Agency for Healthcare Research and Quality (AHRQ); health professions education funding through the Health Resources and Services Administration (HRSA)'s Bureau of Health Professions; and student aid through the Department of Education and HRSA's National Health Service Corps. The AAMC appreciates the subcommittee's longstanding, bipartisan efforts to strengthen these programs.

National Institutes of Health.—The NIH is one of the Federal Government's greatest achievements. Congress's long-standing bipartisan support for medical research through the NIH has created a scientific enterprise that is the envy of the world and has contributed greatly to improving the health and well-being of all Americans. The foundation of scientific knowledge built through NIH-funded research drives medical innovation that improves health through new and better diagnostics, improved prevention strategies, and more effective treatments.

Eighty-four percent of NIH research funding is awarded to more than 2,500 research institutions in every State; at least half of this funding supports life-saving research at America's medical schools and teaching hospitals. This successful partnership not only lays the foundation for improved health and quality of life, but also strengthens the Nation's long-term economy.

The AAMC supports the recommendation of the Ad Hoc Group for Medical Research to recognize NIH as an urgent national priority by providing at least \$32 billion in its fiscal year 2014 Labor-HHS-Education Appropriations bill. Strengthening our Nation's commitment to medical research, through robust funding of the NIH, is a critical element in ensuring the health and well-being of the American people and our economy.

The AAMC notes past proposals by the House subcommittee to reduce the limit on salaries that can be drawn from NIH extramural awards to Executive Level III

⁴U.S. Department of Health and Human Services, National Institutes of Health, *National Cancer Institute 2012 Fact Book*.

⁵American Cancer Society. Facts and Figures 2013. Please note: these figures are not comparable to those published in previous years because as of 2011, the NIH is calculating the estimates using a different data source: the Medical Expenditure Panel Survey (MEPS) of the Agency for Healthcare Research and Quality. The MEPS estimates are based on more current, nationally representative data and are used extensively in scientific publications. As a result, direct and indirect costs will no longer be projected to the current year, and estimates of indirect morbidity costs have been discontinued. For more information, please visit nhlbi.nih.gov/about/factpdf.htm.

of the Federal Executive Pay Scale and thanks the Senate subcommittee for rejecting these efforts. These proposals come at a time when medical schools' and teaching hospitals' discretionary funds from clinical revenues and other sources have become increasingly constrained and less available to invest in research. As institutions and departments divert funds to compensate for the reduction in the salary limit, they will have less funding for critical activities such as bridge funding to investigators who may be between grants and seed grants and start-up packages for young investigators. The lower salary cap will disproportionately affect physician investigators, who will be forced to make up salaries from clinical revenues, thus leaving less time for research. This may serve as a deterrent to their recruitment into research careers. The AAMC urges the subcommittee to retain the limit at Executive Level II.

Agency for Healthcare Research and Quality.—Complementing the medical research supported by NIH, AHRQ sponsors health services research designed to improve the quality of health care by translating research into measurable improvements in the health care system. The AAMC firmly believes in the value of health services research as the Nation continues to strive to provide high quality, efficient health care to all of its citizens. The AAMC joins the Friends of AHRQ in recommending \$434 million for the agency in fiscal year 2014.

As the lead Federal agency to improve health care quality, AHRQ's overall mission is to support research and disseminate information that improves the delivery of health care by identifying evidence-based medical practices and procedures. The Friends of AHRQ funding recommendation will allow AHRQ to continue to support the full spectrum of research portfolios at the agency, from patient safety to other valuable research initiatives. These research findings will better guide and enhance consumer and clinical decisionmaking, provide improved health care services, and promote efficiency in the organization of public and private systems of health care delivery.

Health Professions Funding.—HRSA's Title VII health professions and Title VIII nursing education programs are the only Federal programs designed to improve the supply, distribution, and diversity of the Nation's health care workforce. Through loans, loan guarantees, and scholarships to students, and grants and contracts to academic institutions and non-profit organizations, the Title VII and Title VIII programs fill the gaps in the supply of health professionals not met by traditional market forces. The AAMC joins the Health Professions and Nursing Education Coalition (HPNEC) in recommending \$520 million for these important workforce programs in fiscal year 2014.

Throughout their 50-year history, the Title VII and Title VIII programs have helped the workforce adapt to meet the Nation's changing health care needs. Further, the programs advance timely priorities, such as strengthening education and training opportunities in geriatrics and working to close the gap in access to mental and behavioral health services. Therefore, continued support for the programs is essential to adequately prepare the next generation of health professionals to meet the changing needs of our Nation's growing, aging, and increasingly diverse population.

AAMC is deeply troubled by the President's proposal to eliminate the Title VII Area Health Education Centers (AHEC) and the Title VII Health Careers Opportunity Program (HCOP). As described in the results of a recent AAMC survey, eliminating HCOP will impede programs to assist minority and disadvantaged students in becoming more competitive applicants for health professions training programs and will undermine the positive effects such pipeline programs have on their communities. Similarly, eliminating AHEC will threaten access to primary care for patients in rural and underserved settings by discontinuing support for educational opportunities in these environments. Indeed, failing to support the full range of health professions programs will be counterproductive, disrupting efforts to address some of the country's most pressing health care challenges.

In addition to funding for Title VII and Title VIII, HRSA's Bureau of Health Professions also supports the Children's Hospitals Graduate Medical Education (CHGME) program. This program provides critical Federal graduate medical education support for children's hospitals to prepare the future primary care workforce for our Nation's children and for pediatric specialty care. At a time when the Nation faces a critical doctor shortage, the AAMC strongly objects to the President's fiscal year 2014 proposal to drastically reduce funding for CHGME. AAMC encourages the subcommittee to reject the President's proposal and fully fund the Children's Hospitals Graduate Medical Education program.

Student Aid and the National Health Service Corps (NHSC).—The AAMC urges the committee to sustain student loan and repayment programs for graduate and professional students at the Department of Education. The average graduating debt of medical students is currently \$170,000, and typical repayment can range from

\$321,000 to \$476,000. The Budget Control Act (BCA, Public Law 112-25) adds another \$10,000 to \$20,000 to total repayment as a result of eliminating graduate and professional in-school subsidies, effective July 1, 2012.

The AAMC opposes any rescissions from the National Health Service Corps (NHSC) Fund created under the Affordable Care Act (ACA, Public Law 111-142 and Public Law 111-152). The steady, sustained, and certain growth established by this mandatory funding for the NHSC has resulted in program expansion and innovative pilots such as the Student to Service (S2S) Loan Repayment Program that incentivizes fourth-year medical students to practice primary care in underserved areas after residency training. The AAMC further requests that any expansion of NHSC eligible disciplines or specialties be accompanied by a commensurate increase in NHSC appropriations so as to prevent a reduction of awards to current eligible health professions. Furthermore, the AAMC believes that such changes are best tested through the NHSC State Loan Repayment Program (SLRP), and that funds provided for this program should allow the States to define specialty and geographic shortages.

Once again, the AAMC appreciates the opportunity to submit this statement for the record and looks forward to working with the subcommittee as it prepares its fiscal year 2014 spending bill.

PREPARED STATEMENT OF THE ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

The Association of Independent Research Institutes (AIRI) respectfully submits this written testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. AIRI appreciates the commitment the Members of this subcommittee have made to biomedical research through your strong support for the National Institutes of Health (NIH) and recommends providing at least \$32 billion for NIH in fiscal year 2014. We believe this amount is the minimum level of funding needed to accommodate the rising costs of medical research and to help mitigate the effects of sequestration. AIRI also encourages the subcommittee to work to stop the sequestration cuts to research funding that squander invaluable scientific opportunities, threaten medical progress and continued improvements in our Nation's health, and jeopardize our economic vitality.

AIRI is a national organization of 80 independent, non-profit research institutes that perform basic and clinical research in the biological and behavioral sciences. AIRI institutes vary in size, with budgets ranging from a few million to hundreds of millions of dollars. In addition, each AIRI member institution is governed by its own independent Board of Directors, which allows our members to focus on discovery-based research while remaining structurally nimble and capable of adjusting their research programs to emerging areas of inquiry. Researchers at independent research institutes consistently exceed the success rates of the overall NIH grantee pool, and they receive about 10 percent of NIH's peer-reviewed, competitively-awarded extramural grants.

The reduction of Federal funds to support research, including the 5 percent cut in NIH funding under sequestration, harms our Nation's ability to advance scientific discoveries that improve human health, bolster the economy, and help keep our Nation globally competitive. Furthermore, the impact of sequestration has been compounded by ongoing funding constraints caused by 10 years of flat NIH budgets, which have resulted in a loss of purchasing power and affected the ability of NIH-funded scientists to pursue promising new avenues of research.

At the same time that scientists are facing these funding challenges, they are poised like never before to capitalize on tremendous scientific opportunities and make paradigm-shifting discoveries to address our Nation's most pressing public health needs. Budget uncertainty is disruptive to training, careers, long-range projects, and ultimately, to research progress. To ensure the successful and efficient advancement of science, the research engine needs predictable, sustained funding that maximizes the Nation's return on investment.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 85 percent of NIH funding is spent in communities across the Nation, creating jobs at more than 2,500 research institutes, universities, teaching hospitals, and other institutions. NIH research also supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more. AIRI member institutes are especially vulnerable to reductions in the NIH budget, as they do not have other reliable sources of revenue to make up the shortfall.

In addition to concerns over funding, AIRI member institutes oppose legislative provisions—such as directives to reduce the salary limit for extramural researchers—which would harm the integrity of the research enterprise and disproportionately affect independent research institutes. Such prescriptive policies hinder AIRI members' research missions and their ability to recruit and retain talented researchers. AIRI also does not support legislative language limiting the flexibility of NIH to determine how to most effectively manage its resources while funding the best scientific ideas.

Pursuing New Knowledge.—The NIH model for conducting biomedical research, which involves supporting scientists at universities, medical centers, and independent research institutes, provides an effective approach to making fundamental discoveries in the laboratory that can be translated into medical advances that save lives. AIRI member institutions are private, stand-alone research centers that set their sights on the vast frontiers of medical science. AIRI institutes are specifically focused on pursuing knowledge around the biology and behavior of living systems and applying that knowledge to improve human health and reduce the burdens of illness and disability. Additionally, AIRI member institutes have embraced technologies and research centers to collaborate on biological research for all diseases. Using shared resources—specifically, advanced technology platforms or “cores,”—as well as genomics, imaging, and other technologies, AIRI researchers advance therapeutics development and drug discovery.

Translating Research into Treatments and Therapeutics.—As a network of efficient, flexible independent research institutes that have been conducting translational research for years, AIRI plays a key role in bringing research from the bench to the bedside. The following examples of AIRI members' translational research successes demonstrate the value NIH funding brings to human health:

Scientists at the Fred Hutchinson Cancer Research Center (Seattle, WA) have pioneered a method to improve the use of umbilical cord blood for blood stem cell transplants, a technique that is bringing transplants and cures to many of the 16,000 leukemia patients each year who are unable to find a matching bone marrow donor. In related work, scientists have also developed a strategy to prevent many cases of infection with the virus known as cytomegalovirus, a leading cause of complications and death in cord blood transplant recipients.

Starting with fundamental research on a genetic pathway that blunts the immune response to cancer, scientists at the Lankenau Institute for Medical Research pioneered a new type of drug therapy that destroys a key immune barrier and greatly heightens the efficacy of radiotherapy and chemotherapies used to treat most human cancers. On the basis of groundbreaking proof-of-concept studies at Lankenau, similar inhibitor programs have been started by several pharmaceutical companies. The resulting lead compound has been rated by an NCI workshop as one of the most promising immunotherapeutics in the field, now in Phase Ib/II trials.

Providing Efficiency and Flexibility.—AIRI member institutes' flexibility and research-only missions provide an environment particularly conducive to creativity and innovation. Independent research institutes possess a unique versatility and culture that encourages them to share expertise, information, and equipment across research institutions, as well as neighboring universities. These collaborative activities help minimize bureaucracy and increase efficiency, allowing for fruitful partnerships in a variety of disciplines and industries. Also, unlike institutes of higher education, AIRI member institutes focus primarily on scientific inquiry and discovery, allowing them to respond quickly to the research needs of the country.

Supporting Local Economies.—AIRI is unique from other biomedical research organizations in that our membership consists of institutions located in regions not traditionally associated with cutting-edge research. AIRI members are located in 25 States, including many smaller or less-populated States that do not have major academic research institutions. In many of these regions, independent research institutes are major employers and local economic engines, and they exemplify the positive impact of investing in research and science.

Fostering the Next Generation Scientific Workforce.—The biomedical research community depends upon a knowledgeable, skilled, and diverse workforce to address current and future critical health research questions. While the primary function of AIRI member institutions is research, most are highly involved in training the next generation of biomedical researchers, ensuring that a pipeline of promising scientists is prepared to make significant and potentially transformative discoveries in a variety of areas. AIRI supports policies that promote the ability of the United States to maintain a competitive edge in biomedical science. Initiatives focusing on career development and recruitment of a diverse scientific workforce are important to innovation in biomedical research and public health.

AIRI thanks the subcommittee for its important work dedicated to ensuring the health of the Nation, and we appreciate this opportunity to urge the subcommittee to provide at least \$32 billion for NIH in the fiscal year 2014 appropriations bill. AIRI looks forward to working with Congress to support research that improves the health and quality of life of all Americans.

PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

The Association of Maternal and Child Health Programs (AMCHP) requests for \$640 million in funding for fiscal year 2014 for the Title V Maternal and Child Health (MCH) Services Block Grant administered by the Health Resources and Services Administration Maternal and Child Health Bureau. This funding request represents a \$90 million decrease from its highest level of \$730 million in fiscal year 2003. Nondefense discretionary programs cannot continue to bear the brunt of efforts to reduce the Federal deficit. Specifically, sequestration combined with reductions throughout the past 10 years resulted in at least a \$124 million decrease bringing funding for the Title V MCH Block Grant to its lowest level since 1991. The Title V MCH block grant is the foundation upon which core public health programs dedicated to improving the lives of our families is built and we strongly urge you to halt the erosion of funding for this critical program.

In 2011 the Title V MCH Block Grant provided support and services to 44 million American women, infants and children, including children with special health care needs. It has been proven a cost effective, accountable, and flexible funding source used to address the most critical, pressing and unique MCH needs of each State. States and jurisdictions use the Title V MCH Block Grant to design and implement a wide range of maternal and child health programs. Although specific initiatives may vary among the States and jurisdictions, all of them work with local, State, and national partners to accomplish the following:

- Reduce infant mortality and incidence of disabling conditions among children;
- Increase the number of children appropriately immunized against disease ;
- Increase the number of children in low-income households who receive assessments and follow-up diagnostic and treatment services;
- Provide and ensure access to comprehensive perinatal care for women; preventive and child care services; comprehensive care, including long-term care services, for children with special health care needs; and rehabilitation services for blind and disabled children and
- Facilitate the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs.

In addition to providing services to over 40 million Americans, Title V MCH Block Grant programs save Federal and State governments' money by ensuring that people receive preventive services to avoid more costly chronic conditions later in life. Below are some examples of the cost effectiveness of maternal and child health interventions and the role of this program:

- Total medical costs are lower for exclusively breastfed infants than never-breastfed infants since breastfed infants typically need fewer sick care visits, prescriptions and hospitalizations. State MCH programs promote breastfeeding by developing educational materials for new mothers on breastfeeding practices and providing information on breastfeeding to all residents of their States through websites, toll free telephone lines and coordinating with other local and State programs.
- Studies demonstrate that every \$1 spent on smoking cessation counseling for pregnant women saves \$3 in neonatal intensive care costs. State MCH programs fund State-wide smoking cessation or "quit lines" for pregnant women and provide education within their State about the dangers of smoking during pregnancy, helping moms and moms-to-be quit smoking and reducing their risk of premature birth.
- Every \$1 spent on preconception care programs for women with diabetes can reduce health costs by up to \$5.19 by preventing costly complications in both mothers and babies. Investing \$10 per person per year in community based disease prevention could save more than \$16 billion annually within 5 years. State MCH and chronic disease programs work together at the State and community levels to educate women, children and families about the importance of physical activity, nutrition and obesity prevention throughout the lifespan.
- Early detection of genetic and metabolic conditions can lead to reductions in death and disability as well as saved costs. For example, phenylketonuria

(PKU) a rare metabolic disorder affects approximately one of every 15,000 infants born in the U.S. Studies have found that PKU screening and treatment represent a net direct costs savings. State MCH programs are responsible for assuring that newborn screening systems are in place statewide and that clinicians are alerted when follow up is required.

- Early detection of physical and intellectual disabilities results in more efficient and effective treatment and support for children with special health care needs. High-quality programs for children at risk produce strong economic returns ranging from about \$4 per dollar invested to over \$10 per dollar invested. State MCH programs administer the State and territorial Early Childhood Comprehensive Systems Initiative to support State and community efforts to strengthen, improve and integrate early childhood service systems.
- The injuries incurred by children and adolescents in 1 year create total lifetime economic costs estimated at more than \$50 billion in medical expenses and lost productivity. State MCH programs examine data and translate it into information and policy to positively impact the incidence of infant mortality and other factors that may contribute to child deaths. State MCH programs invest in injury prevention programs, including State and local initiatives to promote the proper use of child safety seats and helmets. Additionally State MCH programs promote safe sleeping practices to prevent Sudden Infant Death Syndrome (SIDS).
- The total cost of adolescent health risk behaviors is estimated to be \$435.4 billion per year. Risky behaviors have impact on the health and well being of adolescents included smoking, binge drinking, substance abuse, suicide attempts and high risk sexual behavior. State MCH programs and their partners address access to health care, violence, mental health and substance use, reproductive health and prevention of chronic disease during adulthood. State MCH programs often support State adolescent health coordinators who work to improve the health of adolescents within their States and territories.

Some Members of Congress contend that savings such as these will not be realized in the near future and therefore will not result in immediate savings in these tight fiscal times. But today we can highlight a real-time example of how the Title V MCH Block Grant has played a role in helping save millions in annual health care costs. In Ohio, Title V played a lead role in providing funding for the Ohio Perinatal Quality Collaborative (OPQC). The OPQC is charged with reducing preterm births and improving outcomes of preterm newborns. Using the Institute for Healthcare Improvement Breakthrough Series, OPQC worked with 20 maternity hospitals (47 percent of all births in the State) through a collaborative focused on several obstetric improvement projects. OPQC reports that as a result of their efforts over 9,000 births are full term and that approximately 250 NICU admissions have been avoided. OPQC estimates approximately \$10 million in annual health care cost savings. Other States have similar initiatives and we are tracking their successes.

Another key component of the Title V MCH Block Grant is the Special Projects of Regional and National Significance (SPRANS). SPRANS funding complements and helps ensure the success of State Title V, Medicaid and CHIP programs by driving innovation, training young professionals and building capacity to create integrated systems of care for mothers and children. Examples of innovative projects funded through SPRANS include guidelines for child health supervision from infancy through adolescence (i.e. Bright Futures); nutrition care during pregnancy and lactation; recommended standards for prenatal care; successful strategies for the prevention of childhood injuries; and health safety standards for out of home childcare facilities.

Without a sustained Federal investment the aforementioned savings will not be realized, program capacity and supports will be diminished and our Nation's ability to address the most pressing needs of these vulnerable populations will not be possible. The Title V MCH Block Grant supports a system which treats a whole person, not by their specific disease and AMCHP strongly urges Congress to sustain this investment at \$640 million in fiscal year 2014.

In addition to the Title V MCH block grant AMCHP is extremely concerned about any future proposals to cut funding from other core programs designed to assure the health of our Nation's families. We strongly urge you to sustain funding for the Centers for Control and Prevention (CDC). It is short sighted and counterproductive to further cut discretionary funding for prevention in the interest of deficit reduction. CDC programs should be protected from further cuts that will have profound consequences on our capacity to address the needs of the most vulnerable.

PREPARED STATEMENT OF THE ASSOCIATION OF MINORITY HEALTH PROFESSIONS
SCHOOLS

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

-
- 1) Title VII Health Professions Training Programs:
 - \$24.602 million for the Minority Centers Of Excellence.
 - \$22.133 million for the Health Careers Opportunity Program.
 - 2) \$32 billion for the National Institutes of Health:
 - Provide proportional increased support for the National Institute on Minority Health and Health Disparities.
 - Provide proportional increased support for Research Centers for Minority Institutions.
 - 3) \$65 million for the Department of Health and Human Services' Office of Minority Health.
 - 4) \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.
-

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you. I am Dr. Wayne J. Riley, Chairman of the Board of Directors of the Association of Minority Health Professions Schools (AMHPS) and the President and Chief Executive Officer of Meharry Medical College. AMHPS, established in 1976, is a consortium of our Nation's twelve (12) historically black medical, dental, pharmacy, and veterinary medicine schools. The members are two dental schools at Howard University and Meharry Medical College; four colleges of medicine at The Charles Drew University, Howard University, Meharry Medical College, and Morehouse School of Medicine; five schools of pharmacy at Florida A&M University, Hampton University, Howard University, Texas Southern University, and Xavier University; and one college of veterinary medicine at Tuskegee University. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help AMHPS continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—entitled “The Rationale for Diversity in the Health Professions: A Review of the Evidence” found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these

areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2014, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)'s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)'s Office of Minority Health (OMH), should be preserved.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. For fiscal year 2014, I recommend a funding level of \$24.602 million for COEs.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2014, I recommend a funding level of \$22.133 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through its Centers of Excellence program. For fiscal year 2014, I recommend funded increases proportional with the funding of the overall NIH, with increased FTEs.

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2014.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, however that role will be greatly diminished if this agency does not retain its grant-making authority. For fiscal year 2014, I recommend a funding level of \$65 million for the OMH.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions.—The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. The funding from this program is used to enhance educational capabilities, establish and strengthen

program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2014, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, AMHPS' member institutions and the Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. The Association seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman.

PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS (APTS)
AND THE PUBLIC BROADCASTING SERVICE (PBS)

On behalf of America's 361 public television stations, we appreciate the opportunity to submit testimony for the record on the importance of Federal funding for local public television stations and PBS. We urge the subcommittee to support level funding of \$445 million in two-year advance funding for the Corporation for Public Broadcasting in fiscal year 2016, and level funding of \$27.3 million for the Ready To Learn program at the Department of Education in fiscal year 2014.

Corporation for Public Broadcasting—fiscal year 2016 Request: \$445 million, two-year advance funded

More than 40 years after the inception of public broadcasting, local stations and PBS continue to serve as the treasured educational and cultural institutions envisioned by their founders, reaching America's local communities with unique, essential and unsurpassed programming and services.

Local stations and PBS treat their audience as citizens rather than mere consumers, providing essential services to all Americans, not just the 18–49 year olds to whom advertisers hope to appeal to. We serve everyone, everywhere, every day, for free.

Public broadcasting serves the public good—in education, public affairs, public safety, the preservation of the national memory and celebration of the American culture, and many other areas—and richly deserves public support. The overwhelming majority of Americans agree. In a recent bi-partisan poll conducted by Hart Research Associates/American Viewpoint, nearly 70 percent of American voters, including majorities of self-identifying Republicans, Independents, and Democrats support continued Federal funding for public broadcasting. In addition, polls shows that Americans consider PBS to be the second most appropriate expenditure of public funds, behind only military defense.

Federal support for CPB and local public television stations has resulted in a nationwide system of locally owned and controlled, trusted, community-driven and community responsive media entities that form an incredibly successful public-private partnership. At an annual cost of about \$1.35 per year for each American, public broadcasting is a smart investment creating important economic activity while providing an essential educational and cultural service. Public media provides a 6 to 1 return on investment for every Federal dollar. In addition, public broadcasting directly supports over 20,000 jobs, and the vast majority of them are in local public television and radio stations in hundreds of communities across America.

We seek Federal funding for public broadcasting because we are part of the Nation's public service infrastructure, just like public libraries, public schools and public highways.

Funding through CPB is absolutely essential to public television stations. Stations rely on the Federal investment to develop local programming, operate their facilities, pay their employees and provide community resources on-air, online and on-the-ground. This funding is particularly important to rural stations that struggle to raise local funds from individual donors due to the smaller and often economically strained population base. At the same time it is often more costly to serve rural areas due to the topography and distances between communities. As a result, public broadcasters, with their commitment to universal service, are often the only local broadcast source for these rural communities.

More than 70 percent of funding appropriated to CPB reaches local stations in the form of Community Service Grants. On average, Federal spending makes up approximately 15 percent of local television station's budgets. However, for many

smaller and rural stations, Federal funding represents more than 30–50 percent (and in a handful of instances, an even larger percentage) of their total budget. For all stations, this Federal funding is the “lifeblood” of public broadcasting, providing critical seed money to local stations that enables them to build additional support from State legislatures, private foundations and corporations, and “viewers like you.”

A 2007 GAO report concluded that these Federal Community Service Grants are an irreplaceable source of revenue, and that “substantial growth of nonFederal funding appears unlikely.” It also found that “cuts in Federal funding could lead to a reduction in staff, local programming or services.” In addition, a June 2012 study requested by this subcommittee and conducted by an independent third party for CPB came to the same conclusion as the GAO: Federal funding for public broadcasting is irreplaceable.

Federal support combined with the advent of digital technology has created enormous potential for stations, allowing them to bring content to Americans in new, innovative ways while retaining our fundamental public service mission. Americans streamed 229 million videos across PBS’ web and mobile platforms in January 2013 alone and in December 2012, 45 percent of all video minutes consumed on kids’ Internet sites were on PBSKIDS.org. Further, public television stations are now utilizing a wide array of digital tools to expand their current roles as educators, local conveners and vital sources of trusted information at a time when their communities need them most.

As the leading source of digital learning tools for America’s preschool teachers and K–12 classrooms with resources to help build science, math and literacy skills, PBS and local stations make-up the Nation’s largest classroom. Local stations provide free, cutting edge, educational content for all Americans so that regardless of their family’s income, children have access to safe, non-commercial media that has helped prepare 90 million American kids for success in school and has been proven to help close the achievement gap.

Stations are also responding to the needs of the 21st century classroom by expanding digital educational resources for teachers, students and parents alike. For example, stations and PBS are working together on PBS Learning Media, an online portal where educators can access standards-based, curriculum-aligned digital learning objects created from public television content as well as material from the Library of Congress, National Archives, and other contributors to the Department of Education’s Learning Registry. Over 28,000 homeschooling families rely on PBS for instructive resources like PBS LearningMedia. Stations are also building home-grown learning platforms like Maryland Public Television’s Thinkport online system, which the State superintendent of schools has credited with helping raise Maryland’s students to the top of the student achievement rankings nationwide.

In their role as community conveners, stations have been working to confront the dropout crisis in America’s high schools. CPB developed the American Graduate initiative, a significant investment and partnership with local stations and their communities to address the daunting high school dropout problem. Stations are providing resources and services to raise awareness, coordinate action with community partners, and work directly with students, parents, teachers, mentors, volunteers and leaders to lower the drop-out rate in their respective communities.

Local public television stations have also embraced the opportunities of digital technology as a way to help address emergency response and homeland security issues in their communities. Stations like Las Vegas PBS have integrated their digital technology with local public safety officials to provide enhanced emergency communications that better aid the responders and provide citizens with needed information during a crisis. Vegas PBS is also the largest job trainer in Nevada, and this manifold mission of service is being emulated by public television stations nationwide.

Local public television stations serve as essential communications hubs in their communities providing unparalleled local coverage of news, current events, and State legislatures that encourages every American to become a more informed citizen. Public television is the place for real public affairs programming, real news, real history, real science, real art that makes us think, teaches us useful things, and inspires us to be a better, more sophisticated, more civilized, more successful people. We bring the wonders of the world—Broadway shows, the finest museums, the best professors and much more—to the most remote places in our country.

In order for our stations to continue playing this vital role in their communities, APTS and PBS respectfully request \$445 million for CPB, two-year advance funded for fiscal year 2016.

Two-year advance funding is essential to the mission of public broadcasting. This longstanding practice, which was proposed by President Ford and embraced by Con-

gress in 1976, establishes a firewall insulating programming decisions from political interference, enables the leveraging of funds to ensure a successful public-private partnership, and provides stations with the necessary lead time to plan in-depth programming.

Public television's history of editorial independence has paid off in unprecedented levels of public trust—for the tenth consecutive year, the American people have ranked PBS as one of the most trusted national institutions. Advance funding and the firewall it provides is vital to maintaining this credibility among the American public.

In addition, local public broadcasting stations are able to leverage the two-year advance funding to raise State, local and private funds, ensuring the continuation of this strong public-private partnership. These Federal funds act as essential seed money for fundraising efforts at every station, no matter its size.

Finally, the two-year advance funding mechanism also gives stations and producers the critical lead time needed to plan and produce high-quality programs. The signature series that demonstrate the depth and breadth of public television, like Ken Burns' *The Civil War* and Henry Hampton's *Eyes on the Prize*, take several years to produce. Ken Burns' documentary schedule is already planned through 2019, and it will educate the Nation on subjects ranging from the Vietnam War to the history of country music.

The fact that stations know they will have funding to support projects like these in advance is critical for producers to be able to actively develop groundbreaking projects. In addition, two-year advance funding is essential to the creation of local programming over multiple fiscal years as stations convene the community to identify needs, recruit partners, conduct research, develop content and deliver services.

The two-year advance funding is essential for stations as they continue to plan the production of the unparalleled programming and local services that educate, inspire, inform and entertain the American people in the unique way only public broadcasting can.

Ready To Learn—fiscal year 2014 Request: \$27.3 million (Department of Education)

The Ready To Learn (RTL) competitive grant program uses the power of public television's on-air, online, mobile and on-the-ground educational content to build the math and reading skills of children between the ages of two and eight, especially those from low-income families. Federal support funds evidence-based television programs and digital content that teach key reading, math and STEM skills, effectively reaching our Nation's children.

Together, CPB and PBS are collaborating with teams of math and literacy experts, technologists, education organizations, and producers, to design and test media that can help close the achievement gap. Numerous studies show that RTL content has a significant and positive effect on the educational lives of children who use it. For example, one study showed that children who watched the RTL-funded PBS series *SUPER WHY!* scored 46 percent higher on standardized tests than those who did not watch the show.

Pivoting off the success in literacy, public media has incorporated early math skills into RTL to help bridge the achievement gap by further innovating educational media content, educating kids inside and outside the classroom, and engaging local communities. Studies have already shown that using RTL content in low-income homes improves pre-school age kids' numerical sense skills. In addition to the content, new tools will be provided including a sophisticated progress tracking system that equips parents and educators with the means to measure student progress, in real time. RTL will continue to be rigorously evaluated for its appeal and efficacy, so that the program can continue to offer America's youngest citizens the tools they need to succeed in school and in life.

In addition to being research-based and teacher tested, the RTL Television program also provides excellent value for our Federal dollars. In the last five-year grant round, public broadcasting leveraged an additional \$50 million in funding to augment the \$73 million investment by the Department of Education for content production. Without the investment of the Federal Government, this supplemental funding would likely end.

In fiscal year 2013 the President's budget proposed consolidating Ready To Learn into a larger grant program. APTS and PBS are concerned that the consolidation of this program would end the ground-breaking educational impact that RTL has had on kids nationwide, and particularly those with limited access to other educational resources. Consolidation would deny RTL the benefits that come from the unique understanding of needs and relationship that local public media stations have with the communities they serve. At the same time, consolidation undermines PBS's ability to create television and online content on an economy of scale that re-

sults from producing once for national distribution through member stations who can tailor outreach to the demands of their communities. This model allows PBS and local stations to annually reach 80 percent of America's children ages 2 to 8 through television and another 13 million per month online and on mobile apps. The local-national partnership has made RTL tremendously efficient and effective and consolidation or elimination of the program would severely affect the ability of local stations to respond to their communities' educational needs, eliminating the critical resources provided by this program for children, parents and teachers.

Ready To Learn symbolizes the mission of public media and is a shining example of a public-private partnership as Federal funds are leveraged to create the most appealing and impactful children's educational content that is supplemented by on-line and on-the-ground resources. Without the Ready To Learn program, millions of families would lose access to this incredible high-quality education content, especially the low-income and underserved households that are a particular focus of this program.

One hundred seventy million Americans regularly rely on public broadcasting—on television, on the radio, online, and in the classroom—because we provide them something they need that no one else in the media world provides: A place to think. A place to learn. A place to grow. A tool for the citizen. None of this would be possible without the Federal investment in public broadcasting.

We request that Congress continue its commitment to this highly successful public-private partnership by continuing to provide level funding for the two-year advance of the Corporation for Public Broadcasting and the stand alone Ready To Learn Program.

PREPARED STATEMENT OF THE ASSOCIATION OF REHABILITATION NURSES

INTRODUCTION

On behalf of the Association of Rehabilitation Nurses (ARN), I appreciate having the opportunity to submit written testimony to the Senate LHHS Appropriations Subcommittee regarding funding for nursing and rehabilitation related programs in fiscal year 2014. ARN represents nearly 12,000 rehabilitation nurses that work to enhance the quality of life for those affected by physical disability and/or chronic illness. ARN understands that Congress has many concerns and limited resources, but believes that chronic illnesses and physical disabilities are heavy burdens on our society that must be addressed.

REHABILITATION NURSES AND REHABILITATION NURSING

Rehabilitation nurses help individuals affected by chronic illness and/or physical disability adapt to their condition, achieve their greatest potential, and work toward productive, independent lives. We take a holistic approach to meeting patients' nursing and medical, vocational, educational, environmental, and spiritual needs. Rehabilitation nurses begin to work with individuals and their families soon after the onset of a disabling injury or chronic illness. They continue to provide support and care, including patient and family education, which empowers these individuals when they return home, or to work, or school. The rehabilitation nurse often teaches patients and their caregivers how to access systems and resources.

Rehabilitation nursing is a philosophy of care, not a work setting or a phase of treatment. We base our practice on rehabilitative and restorative principles by: (1) managing complex medical issues; (2) inter professional collaboration with other specialists; (3) providing ongoing patient/caregiver education; (4) setting goals for maximum independence; and (5) establishing plans of care to maintain optimal wellness. Rehabilitation nurses practice in all settings, including freestanding rehabilitation facilities, hospitals, long-term subacute care facilities/skilled nursing facilities, long-term acute care facilities, comprehensive outpatient rehabilitation facilities, home health, and private practices, just to name a few.

As we celebrate the third anniversary of the Affordable Care Act (ACA)—which focused on creating a system that will increase access to quality care, emphasizes prevention, and decreases costs—it is critical that a substantial investment be made in the nursing workforce programs and in the scientific research that provides the basis for nursing practice. To ensure that patients receive the best quality care possible, ARN supports Federal programs and research institutions that address the national nursing shortage and conduct research focused on nursing and medical rehabilitation, e.g., traumatic brain injury. Therefore, ARN respectfully requests that the subcommittee provide increased funding for the following programs:

NURSING WORKFORCE AND DEVELOPMENT PROGRAMS AT THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

ARN supports efforts to resolve the national nursing shortage, including appropriate funding to address the shortage of qualified nursing faculty. Rehabilitation nursing requires a high-level of education and technical expertise, and ARN is committed to assuring and protecting access to professional nursing care delivered by highly-educated, well-trained, and experienced registered nurses for individuals affected by chronic illness and/or physical disability.

According to the Bureau of Labor Statistics' Employment Projections for 2010–2020, the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26 percent. The projections further explain the need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020. The demand for nurses will continue to grow as the baby-boomer population ages, nurses retire, and the need for healthcare intensifies. Implementation of the new health reform law will also increase the need for a well-trained and highly skilled nursing workforce. The Institute of Medicine has released recommendations on how to help the nursing workforce meet these new demands, but we are destined to fall short of these lofty goals if there are not enough nurses to facilitate change.

For nearly 50 years, the Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare needs. The Title VIII programs bolster nursing education at all levels, from entry-level preparation through graduate study, and provide support for institutions that educate nurses for practice in rural and medically underserved communities. Today, the Title VIII programs are essential to ensure the demand for nursing care is met. Between fiscal year 2005 and 2010 alone, the Title VIII programs supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions, and healthcare facilities. Educating new nurses to fill these vacancies is a great way to put Americans back to work and simultaneously enhance an ailing health care system.

ARN strongly supports the national nursing community's request of \$251 million in fiscal year 2014 funding for Federal Nursing Workforce Development programs at HRSA.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR)

The National Institute on Disability and Rehabilitation Research (NIDRR) provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. As one of the components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education, NIDRR operates along with the Rehabilitation Services Administration and the Office of Special Education Programs.

The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities. NIDRR conducts comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as: employment, health and function, technology for access and function, independent living and community integration, and other associated disability research areas.

ARN strongly supports the work of NIDRR and encourages Congress to provide the maximum possible fiscal year 2014 funding level.

NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

ARN understands that research is essential for the advancement of nursing science, and believes new concepts must be developed and tested to sustain the continued growth and maturation of the rehabilitation nursing specialty. The National Institute of Nursing Research (NINR) works to create cost-effective and high-quality health care by testing new nursing science concepts and investigating how to best integrate them into daily practice. Through grants, research training, and inter professional collaborations, NINR addresses care management of patients during illness and recovery, reduction of risks for disease and disability, promotion of healthy lifestyles, enhancement of quality of life for those with chronic illness, and care for individuals at the end of life. NINR's broad mandate includes seeking to prevent and

delay disease and to ease the symptoms associated with both chronic and acute illnesses. NINR's recent areas of research focus include the following:

- End of life and palliative care in rural areas;
- Research in multi-cultural societies;
- Bio-behavioral methods to improve outcomes research; and
- Increasing health promotion through comprehensive studies.

ARN respectfully requests \$150 million in fiscal year 2014 funding for NINR to continue its efforts to address issues related to chronic and acute illnesses.

TRAUMATIC BRIAN INJURY (TBI)

According to the Brain Injury Association of America, 1.7 million people sustain a traumatic brain injury (TBI) each year.¹ This figure does not include the 150,000 cases of TBI suffered by soldiers returning from wars in Afghanistan and conflicts around the world.

The annual national cost of providing treatment and services for these patients is estimated to be nearly \$60 million in direct care and lost workplace productivity. Continued fiscal support of the Traumatic Brain Injury Act will provide critical funding needed to further develop research and improve the lives of individuals who suffer from traumatic brain injury.

Continued funding of the TBI Act will promote sound public health policy in brain injury prevention, research, education, treatment, and community-based services, while informing the public of needed support for individuals living with TBI and their families.

ARN strongly supports the current work being done by the Centers for Disease Control and Prevention (CDC) and HRSA on TBI programs. These programs contribute to the overall body of knowledge in rehabilitation medicine.

ARN urges Congress to support the following fiscal year 2014 funding requests for programs within the TBI Act: \$10 million for CDC's TBI registries and surveillance, prevention and national public education and awareness efforts; \$8 million for the HRSA Federal TBI State Grant Program; and \$4 million for the HRSA Federal TBI Protection and Advocacy Systems Grant Program.

CONCLUSION

ARN appreciates the opportunity to share our priorities for fiscal year 2014 funding levels for nursing and rehabilitation programs. ARN maintains a strong commitment to working with Members of Congress, other nursing and rehabilitation organizations, and other stakeholders to ensure that the rehabilitation nurses of today continue to practice tomorrow. By providing the fiscal year 2014 funding levels detailed above, we believe the subcommittee will be taking the steps necessary to ensure that our Nation has a sufficient nursing workforce to care for patients requiring rehabilitation from chronic illness and/or physical disability.

PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY (AUPOHS)

I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), an organization representing the 18 multidisciplinary, university-based Education and Research Centers (ERCs) and the nine Agricultural Centers for Disease and Injury Research, Education, and Prevention funded by the National Institute for Occupational Safety and Health (NIOSH), the Federal agency responsible for supporting education, training, and research for the prevention of work-related injuries and illnesses in the United States.

We respectfully request that the fiscal year 2014 Labor, Health and Human Services Appropriations bill include level funding of \$24.268 million for the Education and Research Centers and \$22 million for the Agriculture, Forestry and Fishing Program within the NIOSH budget.

The ERCs are regional resources for parties involved with occupational health and safety—industry, labor, Government, academia, and the public. Collectively, the ERCs provide training and research resources to every Public Health Region in the United States. ERCs contribute to national efforts to reduce losses associated with work-related illnesses and injuries by offering:

Prevention Research.—Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.

¹ <http://www.biausa.org/living-with-brain-injury.htm>.

Professional Training.—ERC's support 86 graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, Industrial Hygiene, and other related fields to provide qualified professionals in essential disciplines.

Research Training.—Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.

Continuing Education.—Short courses designed to enhance professional skills and maintain professional certification for those who are currently practicing in occupational health and safety disciplines. These courses are delivered throughout the regions of the 18 ERCs as well as through distance learning technologies.

Regional Outreach.—Responding to specific requests from local employers and workers on issues related to occupational health and safety.

Occupational injury and illness represent a striking burden on America's health and well-being. Despite significant improvements in workplace safety and health over the last several decades, each year nearly 1.2 million workers are injured seriously enough to require time off work and, daily, an average of 11,000 U.S. workers sustain disabling injuries on the job, 13 workers die from an injury suffered at work, and 146 workers die from work-related diseases. This burden costs industry and citizens an estimated \$4 billion per week—\$250 billion dollars per year. This is an especially tragic situation because work-related fatalities, injuries and illnesses are preventable with effective, professionally directed, health and safety programs.

The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, between 2000 and 2015, the number of workers 55 years and older will increase 72 percent to over 31 million. Work related injury and fatality rates increase at age 45, with rates for workers 65 years and older nearly three times greater than younger workers. In addition to changing demographics, the rapid development of new technologies (e.g., nanotechnology) poses many unanswered questions with regard to workplace health and safety that require urgent attention.

The heightened awareness of terrorist threats, and the increased responsibilities of first responders and other homeland security professionals, illustrates the need for strengthened workplace health and safety in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing occupational safety and health professionals to identify and mitigate vulnerabilities to terrorist attacks and to increase readiness to respond to biological, chemical, or radiological attacks. In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize disaster losses. For example, NIOSH took a lead role in protecting the safety of 9/11 emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and to implement evidence-based programs to safeguard the health of clean-up workers. Additionally, NIOSH is now administering grants to provide health screening of World Trade Center responders. We need manpower to address these challenges and it is the NIOSH ERCs that train the professionals who fill key positions in health and safety programs, regionally and around the Nation. And because ERCs provide multi-disciplinary training, ERC graduates protect workers in virtually every walk of life. Despite the success of the ERCs in training such qualified professionals, the country continues to have ongoing manpower shortages.

The Agricultural Safety and Health Centers program was established by Congress in 1990 (Public Law 101-517) in response to evidence that agricultural workers were suffering substantially higher rates of occupational injury and illness than other U.S. workers.

Today the NIOSH Agriculture, Forestry, and Fishing (AFF) Initiative includes nine regional Centers for Agricultural Disease and Injury Research, Education, and Prevention and one national center to address children's farm safety and health. The AFF program is the only substantive Federal effort to meet the obligation to ensure safe working conditions for workers in this most vital production sector. While agriculture, forestry, and fishing constitute one of the largest industry sectors in the U.S. (DOL 2011), most AFF operations are themselves small: nearly 78 percent employ fewer than 10 workers, and most rely on family members and/or immigrant, part-time, contract and seasonal labor. Thus, many AFF workers are excluded from labor protections, including many of those enforced by OSHA.

In 2010 the AFF sector had a work-related fatality rate of 28 per 100,000 workers, the highest of any sector in the Nation. More than 1 in 100 AFF workers incur nonfatal injuries resulting in lost work days each year. These reported figures do not even include men, women, and youths on farms with fewer than 11 full-time

employees. In addition to the harm to individual men, women, and families, these deaths and injuries inflict serious economic losses including medical costs and lost capital, productivity, and earnings. The life-saving, cost-effective work of the NIOSH AFF program is not replicated by any other agency:

- State and Federal OSHA personnel rely on NIOSH research in the development of evidence-based standards for protecting agricultural workers and would not be able to fulfill their mission without the NIOSH AFF program.
- While committed to the well-being of farmers, the USDA has little expertise in the medical or public health sciences. USDA no longer funds, as it did historically, land grant university-based farm safety specialists.
- Staff members of USDA's National Institute of Food and Agriculture interact with NIOSH occupational safety and health research experts to keep abreast of cutting-edge research and new directions in this area.

NIOSH Agricultural Center activities include:

- AFF research has shown that the use of rollover protective structures (ROPS or rollbars) and seatbelts on tractors can prevent 99 percent of overturn-related deaths. A New York program has increased the installation of ROPS by 10-fold and recorded over 100 close calls with no injuries among farmers who had installed ROPS. 99 percent of program participants said they would recommend the program to other farmers.
- Working in partnership with producers and farm owners, the NIOSH AFF Centers have developed evidence-based solutions for reducing exposure to pesticides and other farm chemicals among farmers, farm workers and their children.
- Commercial Fishing had a reported annual fatality rate 58 times higher than the rate for all U.S. workers in 2009. Research has shown that knowledge of maritime navigation rules and emergency preparedness means survival. A NIOSH AFF-funded team produced an interactive navigation training CD in three languages, demonstrated the effectiveness of refresher survival drill instruction, and assisted the U.S. Coast Guard's revision of regulations requiring commercial fishing vessel captains completed navigation training.
- The Centers have partnered with producers, employers, the Federal migrant health program, physicians, nurses, and Internet Technology specialists to educate farmers, employers, and health care providers about the best way to treat and prevent agricultural injury and illness.
- In 2010, the logging industry had a reported fatality rate of 91.9 deaths per 100,000 workers (preliminary data), a rate more than 25 times higher than that of all U.S. workers. NIOSH AFF Centers including the Southeast and the Northwest are uniquely positioned to ensure the safety of our Nation's 86,000 workers in forestry & logging.

Thank you for the opportunity to present testimony on behalf of the many individuals committed to working to improve the safety and well being of others in our communities.

PREPARED STATEMENT OF THE ASSOCIATION OF ZOOS AND AQUARIUMS

Chairman Harkin and Ranking Member Moran: My name is Jim Maddy, and I am the President and CEO. Thank you for allowing me to testify on behalf of the Nation's 211 U.S. accredited zoos and aquariums. Specifically, I want to express my support for the inclusion of \$38.6 million for the Institute of Museum and Library Services' (IMLS) Office of Museum Services in the fiscal year 2014 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Founded in 1924, the Association of Zoos and Aquariums (AZA) is a nonprofit 501(c)(3) organization dedicated to the advancement of zoos and aquariums in the areas of conservation, education, science, and recreation. Accredited zoos and aquariums annually see more than 182 million visitors, collectively generate more than \$16 billion in annual economic activity, and support more than 142,000 jobs across the country. Over the last 5 years, AZA-accredited institutions supported more than 4,000 field conservation and research projects with \$160,000,000 annually in more than 100 countries. In the last 10 years, accredited zoos and aquariums formally trained more than 400,000 teachers, supporting science curricula with effective teaching materials and hands-on opportunities. School field trips annually connect more than 12,000,000 students with the natural world.

Aquariums and zoological parks are defined by the "Museum and Library Services Act of 2003" (Public Law 108-81) as museums. The Office of Museum Services awards grants to museums to support them as institutions of learning and exploration, and keepers of cultural, historical, and scientific heritages. Grants are

awarded in several areas including educational programming, professional development, and collections management, among others.

The Nation's accredited zoos and aquariums, even while facing budget limitations, are thriving during these uncertain economic times. As valued members of local communities, zoos and aquariums offer a variety of programs ranging from unique educational opportunities for schoolchildren to conservation initiatives that benefit both local and global species. The competitive grants offered by the IMLS Office of Museum Services ensure that many of these programs, which otherwise may not exist because of insufficient funds, positively impact local communities and many varieties of species.

For example, through its 2012 Museums for America grant, the Birmingham Zoo will support its Africa Zoo School program, which will serve 1,200 students over 2 years. Partnering with Birmingham City School, seventh-grade students from low-performing schools attend a week-long "Zoo School" session, where they learn about the crisis of the elephant species' survival in Africa, the cultures of people in Africa, and the scientific and engineering research involved in sustaining these populations. A 2011 Museums for America grant enabled The National Aquarium in Baltimore to create a more robust volunteer program by developing and testing new techniques to attract, train, engage, and retain a new generation of more diverse volunteers. Finally, the Beardsley Zoo used its 2011 Museums for America grant to continue its "Conservation Discovery Corps" teen program, a year-round informal science education program designed to provide diverse and economically challenged but environmentally aware students with applied wildlife conservation training in the zoo and through field research. Students were trained in conservation and education concepts that were applied through field expeditions and collaborations with scientists in research and habitat restoration activities to prepare them as zoo exhibit interpreters and teen Conservation Discovery Corps ambassadors.

Unfortunately, current funding has allowed IMLS to fund only a small fraction of all highly-rated grant applications. Despite this funding shortfall, zoo and aquarium attendance has increased and the educational services zoos and aquariums provide to schools and communities are in greater demand than ever. Zoos and aquariums are essential partners at the Federal, State, and local levels in providing education and cultural opportunities that adults and children may otherwise never enjoy.

As museums, zoos and aquariums share the same mission of preserving the world's great treasures, educating the public about them, and contributing to the Nation's economic and cultural vitality. Therefore, I strongly encourage you to include \$38.6 million for the Institute of Museum and Library Services' Office of Museum Services in the fiscal year 2014 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.

Thank you.

PREPARED STATEMENT OF THE BRAIN INJURY ASSOCIATION OF AMERICA

Chairman Harkin and Ranking Member Moran, thank you for the opportunity to submit this written testimony with regard to the fiscal year 2014 Labor-HHS-Education appropriations bill. This testimony is on behalf of the Brain Injury Association of America (BIAA), our national network of State affiliates, and hundreds of local chapters and support groups from across the country.

In the civilian population alone every year, more than 1.7 million people sustain brain injuries from falls, car crashes, assaults and contact sports. Males are more likely than females to sustain brain injuries. Children, teens and seniors are at greatest risk.

Recently, we are seeing an increasing number of service members returning from the conflicts in Iraq and Afghanistan with TBI, which has been termed one of the signature injuries of the War. Many of these returning service members are undiagnosed or misdiagnosed and subsequently they and their families will look to community and local resources for information to better understand TBI and to obtain vital support services to facilitate successful reintegration into the community.

For the past 14 years Congress has provided minimal funding through the HRSA Federal TBI Program to assist States in developing services and systems to help individuals with a range of service and family support needs following their loved one's brain injury. Similarly, the grants to State Protection and Advocacy Systems to assist individuals with traumatic brain injuries in accessing services through education, legal and advocacy remedies are woefully underfunded. Rehabilitation, community support and long-term care systems are still developing in many States, while stretched to capacity in others. Additional numbers of individuals with TBI

as the result of war-related injuries only adds more stress to these inadequately funded systems.

BIAA respectfully urges you to provide States with the resources they need to address both the civilian and military populations who look to them for much needed support in order to live and work in their communities.

With broader regard to all of the programs authorized through the TBI Act, BIAA specifically requests:

- \$10 million (+ \$4 million) for the Centers for Disease Control and Prevention TBI Registries and Surveillance, Brain Injury Acute Care Guidelines, Prevention and National Public Education/Awareness
- \$8 million (+ \$1 million) for the Health Resources and Services Administration (HRSA) Federal TBI State Grant Program
- \$4 million (+ \$1 million) for the HRSA Federal TBI Protection & Advocacy (P&A) Systems Grant Program

CDC—National Injury Center.—The Centers for Disease Control and Prevention's National Injury Center is responsible for assessing the incidence and prevalence of TBI in the United States. The CDC estimates that 1.7 million TBIs occur each year and 3.4 million Americans live with a life-long disability as a result of TBI. In addition, the TBI Act as amended in 2008 requires the CDC to coordinate with the Departments of Defense and Veterans Affairs to include the number of TBIs occurring in the military. This coordination will likely increase CDC's estimate of the number of Americans sustaining TBI and living with the consequences.

CDC also funds States for TBI registries, creates and disseminates public and professional educational materials, for families, caregivers and medical personnel, and has recently collaborated with the National Football League and National Hockey League to improve awareness of the incidence of concussion in sports. CDC plays a leading role in helping standardize evidence based guidelines for the management of TBI and \$1 million of this request would go to fund CDC's work in this area.

HRSA TBI State Grant Program.—The TBI Act authorizes the HHS, Health Resources and Service Administration (HRSA) to award grants to (1) States, American Indian Consortia and territories to improve access to service delivery and to (2) State Protection and Advocacy (P&A) Systems to expand advocacy services to include individuals with traumatic brain injury. For the past thirteen years the HRSA Federal TBI State Grant Program has supported State efforts to address the needs of persons with brain injury and their families and to expand and improve services to underserved and unserved populations including children and youth; veterans and returning troops; and individuals with co-occurring conditions

In fiscal year 2009, HRSA reduced the number of State grant awards to 15, in order to increase each monetary award from \$118,000 to \$250,000. This means that many States that had participated in the program in past years have now been forced to close down their operations, leaving many unable to access brain injury care.

Increasing the program to \$8 million will provide funding necessary to sustain the grants for the 21 States currently receiving funding along with the three additional States added this year and to ensure funding for four additional States. Steady increases over 5 years for this program will provide for each State including the District of Columbia and the American Indian Consortium and territories to sustain and expand State service delivery; and to expand the use of the grant funds to pay for such services as Information & Referral (I&R), systems coordination and other necessary services and supports identified by the State.

HRSA TBI P&A Program.—Similarly, the HRSA TBI P&A Program currently provides funding to all State P&A systems for purposes of protecting the legal and human rights of individuals with TBI. State P&As provide a wide range of activities including training in self-advocacy, outreach, information & referral and legal assistance to people residing in nursing homes, to returning military seeking veterans benefits, and students who need educational services.

Effective Protection and Advocacy services for people with traumatic brain injury is needed to help reduce Government expenditures and increase productivity, independence and community integration. However, advocates must possess specialized skills, and their work is often time-intensive. A \$4 million appropriation would ensure that each P&A can move towards providing a significant PATBI program with appropriate staff time and expertise.

NIDRR TBI Model Systems of Care.—Funding for the TBI Model Systems in the Department of Education is urgently needed to ensure that the Nation's valuable TBI research capacity is not diminished, and to maintain and build upon the 16 TBI Model Systems research centers around the country.

The TBI Model Systems of Care program represents an already existing vital national network of expertise and research in the field of TBI, and weakening this pro-

gram would have resounding effects on both military and civilian populations. The TBI Model Systems are the only source of non-proprietary longitudinal data on what happens to people with brain injury. They are a key source of evidence-based medicine, and serve as a “proving ground” for future researchers.

In order to make this program more comprehensive, Congress should provide \$11 million (+ \$1.5 million) in fiscal year 2014 for NIDRR’s TBI Model Systems of Care program, in order to add one new Collaborative Research Project. In addition, given the national importance of this research program, the TBI Model Systems of Care should receive “line-item” status within the broader NIDRR budget.

We ask that you consider favorably these requests for the CDC, the HRSA Federal TBI Program, and the NIDRR TBI Model Systems Program to further data collection, increase public awareness, improve medical care, assist States in coordinating services, protect the rights of persons with TBI, and bolster vital research.

PREPARED STATEMENT OF THE CENTERS FOR DISEASE CONTROL AND PREVENTION
(CDC) COALITION

The CDC Coalition is a nonpartisan coalition of more than 140 organizations committed to strengthening our Nation’s prevention programs. We represent millions of public health workers, clinicians, researchers, educators, and citizens served by CDC programs.

The CDC Coalition believes that Congress should support CDC as an agency—not just the individual programs that it funds. Given the challenges and burdens of chronic disease and disability, constant public health emergencies, new and re-emerging infectious diseases and other unmet public health needs—we urge a funding of \$7.8 billion for CDC’s programs in fiscal year 2014. Unfortunately, the President’s fiscal year 2014 budget request for CDC represents a nearly \$277 million reduction when compared with fiscal year 2012. These proposed cuts come on top of the \$577 million reduction to CDC in fiscal year 2013 due to the sequester and reduction in Prevention and Public Health Fund resources. After these cuts, CDC’s budget authority is now lower than 2003 levels. At the same time, State and local health departments are operating on tight budgets and with a smaller workforce. Cuts to CDC’s programs are not sustainable and will reduce the ability to investigate and respond to public health emergencies as well as food borne and infectious disease

By translating research findings into effective intervention efforts, CDC has been a key source of funding for many of our State and local programs that aim to improve the health of communities. Federal funding through CDC provides the foundation for State and local public health departments, supporting a trained workforce, laboratory capacity and public health education communications systems.

CDC serves as the command center for our Nation’s public health defense system, conducting surveillance and detection of emerging and reemerging infectious diseases. With the potential onset of a worldwide influenza pandemic, in addition to the many other natural and man-made threats that exist in the modern world, CDC is the Nation’s expert resource and response center, coordinating communications and action and serving as the laboratory reference center for identifying, testing and characterizing potential agents of biological, chemical and radiological terrorism, emerging infectious diseases and other public health emergencies. CDC serves as the lead agency for bioterrorism and public health emergency preparedness and must receive sustained support for its preparedness programs to meet future challenges. We urge you to provide adequate funding for CDC’s emergency preparedness and response activities.

Heart disease remains the Nation’s No. 1 killer. In 2010, over 597,000 people in the U.S. died from heart disease, accounting for nearly 25 percent of all U.S. deaths. More males than females died of heart disease in 2010 (307,384 compared to 290,305), while more females than males died of stroke that year (77,109 compared to 52,367). Stroke is the fourth leading cause of death and is a leading cause of disability. In 2010, about 129,000 people died of stroke (60 percent of them females), accounting for about 1 of every 19 deaths. CDC’s Heart Disease and Stroke Prevention Program, WISEWOMAN, and the Million Hearts program are working improve cardiovascular health.

Cancer is the second most common cause of death in the United States. There are 1,660,290 new cancer cases and 580,350 deaths from cancer expected in 2013. According to the

National Institutes of Health, in 2008 the overall cost for cancer in the U.S. was more than \$201.5 billion: \$77.4 billion for direct medical costs, \$124.0 billion for indirect mortality costs (cost of lost productivity due to premature death). CDC’s Na-

tional Breast and Cervical Cancer Early Detection Program helps millions of low-income, uninsured and medically underserved women gain access to lifesaving breast and cervical cancer screenings and provides a gateway to treatment upon diagnosis. CDC also funds grants to all 50 States to develop Comprehensive Cancer Control plans, bringing together a broad partnership of public and private stakeholders to set joint priorities and implement specific cancer prevention and control activities customized to address each State's particular needs.

Although more than 25.8 million Americans have diabetes, nearly 7 million cases are undiagnosed. In 2010, about 1.9 million people aged 20 years or older were newly diagnosed with diabetes. Diabetes is the leading cause of kidney failure, non-traumatic lower-limb amputations, and new cases of blindness among adults in the U.S. The total direct and indirect costs associated with diabetes were \$245 billion in 2012. CDC's Division of Diabetes Translation funds critical diabetes prevention, surveillance and control programs.

Arthritis is the most common cause of disability in the U.S., striking 50 million Americans of all ages, races and ethnicities. CDC's Arthritis Program plays a critical role in addressing this growing public health crisis and working to improve the quality of life for individuals affected by arthritis.

Over the last 20 years, obesity rates have dramatically increased and rates remain high. More than one third of adults are obese and 17 percent of children between the ages of 2–19 are obese. Obesity, diet and inactivity are cross-cutting risk factors that contribute significantly to heart disease, cancer, stroke and diabetes. CDC funds programs to encourage the consumption of fruits and vegetables, encourage sufficient exercise, and to develop other habits of healthy nutrition and activity.

An estimated 443,000 people die prematurely every year due to tobacco use. CDC's tobacco control efforts seek to prevent tobacco addiction in the first place, as well as help those who want to quit. We must continue to support these vital programs and reduce tobacco use in the United States.

According to CDC, only one out of three high school students participate in daily physical education classes and one in three children and adolescents are overweight or obese. And every year, more than 400,000 teen girls give birth and nearly half of all sexually transmitted diseases occur in young people between the ages of 15 and 24. CDC plays a critical role in ensuring good public health and health promotion in our Nation's schools.

CDC provides national leadership in helping control the HIV epidemic by working with community, State, national, and international partners in surveillance, research, prevention and evaluation activities. CDC estimates that about 1.1 million Americans are living with HIV, 18 percent of who are undiagnosed. Also, the number of people living with HIV is increasing, as new drug therapies are keeping HIV-infected persons healthy longer and dramatically reducing the death rate. Prevention of HIV transmission is the best defense against the AIDS epidemic that has already killed more than 636,000 in the U.S. and is devastating populations around the globe.

The U.S. has the highest rates of sexually transmitted diseases in the industrialized world. More than 19 million new infections occur each year. CDC estimates that STDs, including HIV, cost the U.S. healthcare system as much as \$17 billion annually. An adequate investment in CDC's STD prevention programs could save millions in annual health care costs in the future.

The National Center for Health Statistics collects data on chronic disease prevalence, health disparities, emergency room use, teen pregnancy, infant mortality and causes of death. The health data collected through the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, Youth Tobacco Survey, National Vital Statistics System, and National Health and Nutrition Examination Survey are an essential part of the Nation's statistical and public health infrastructure and must be adequately funded.

CDC oversees immunization programs for children, adolescents and adults, and is a global partner in the ongoing effort to eradicate polio worldwide. Influenza vaccination levels remain low for adults. Levels are substantially lower for pneumococcal vaccination among adults as well, with significant racial and ethnic disparities in vaccination levels persisting among the elderly. Childhood immunizations provide one of the best returns on investment of any public health program. For every dollar spent on childhood vaccines to prevent thirteen diseases, \$10.20 is saved in direct and indirect costs. An estimated 20 million cases of disease and 42,000 deaths are prevented each year through timely immunization. Despite the incredible success of the program, it faces serious financial challenges.

Injuries are the leading causes of death for persons aged 1–44 years. Unintentional injuries and violence such as older adult falls, unintentional drug poisonings, child maltreatment and sexual violence accounts for over 35 percent of emergency

department visits annually. Annually, injury and violence cost the U.S. approximately \$406 billion in direct and indirect medical costs including lost productivity. CDC's Injury Center works to prevent injuries and to minimize their consequences when they occur by researching the problem, identifying the risk and protective factors, developing and testing interventions and ensuring widespread adoption of proven prevention strategies.

One in every 33 babies born each year in the U.S. is born with one or more birth defects. Birth defects are the leading cause of infant mortality. Children with birth defects who survive often experience lifelong physical and mental disabilities. More than 50 million people in the U.S. currently live with a disability, and 17 percent of children under the age of 18 have a developmental disability. The National Center on Birth Defects and Developmental Disabilities conducts programs to protect and improve health by preventing birth defects and developmental disabilities.

CDC's National Center for Environmental Health is essential to protecting and ensuring the health and well being of the American public by helping to control asthma, protecting from threats associated with natural disasters and climate change and reducing exposure to lead and other environmental hazards. To ensure it can carry out these vital programs, we ask you to support and restore adequate funding for NCEH which has been cut by nearly 25 percent since 2010.

In order to meet the ongoing public health challenges outlined above, we urge you to adopt our fiscal year 2014 request of \$7.8 billion for CDC's programs.

PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND
SCIENCE

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) Provide funding for the Health Resources and Services Administration Title VII Health Professions Training Programs, including:
 - \$24.602 million for the Minority Centers of Excellence.
 - \$22.133 million for the Health Careers Opportunity Program.
 - 2) \$32 billion for the National Institutes of Health (NIH), specifically:
 - Proportional increase for the National Institute on Minority Health and Health Disparities (NIMHD).
 - Proportional increase for the Research Centers at Minority Institutions Program.
 - 3) \$65 Million for the Department of Health and Human Services' Office of Minority Health.
 - 4) \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.
-

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present you with testimony. The Charles Drew University is distinctive in being the only dually designated Historically Black Graduate Institution and Hispanic Serving Institution in the Nation. We would like to thank you, Mr. Chairman, for the support that this subcommittee has given to our University to produce minority health professionals to eliminate health disparities as well as do groundbreaking research to save lives.

The Charles Drew University is located in the Watts-Willowbrook area of South Los Angeles. Its mission is to prepare predominantly minority doctors and other health professionals to care for underserved communities with compassion and excellence through education, clinical care, outreach, pipeline programs and advanced research that makes a rapid difference in clinical practice. The Charles Drew University has established a national reputation for translational research that addresses the health disparities and social issues that strike hardest and deepest among urban and minority populations.

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Title VII Health Professions Training Programs.—The health professions training programs administered by the Health Resources and Services Administration (HRSA) are the only Federal initiatives designed to address the longstanding under representation of minorities in health careers. HRSA's own report, "The Rationale for Diversity in the Health Professions: A Review of the Evidence," found that minority health professionals disproportionately serve minority and other medically underserved populations, minority populations tend to receive better care from practitioners of their own race or ethnicity, and non-English speaking patients experi-

ence better care, greater comprehension and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health professions institutions, they are significantly more likely to: 1) serve in medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

Minority Centers of Excellence.—The purpose of the COE program is to assist schools, like Charles Drew University, that train minority health professionals, by supporting programs of excellence. The COE program focuses on improving student recruitment and performance; improving curricula and cultural competence of graduates; facilitating faculty and student research on minority health issues; and training students to provide health services to minority individuals by providing clinical teaching at community-based health facilities. For fiscal year 2014, the funding level for COE should be \$24.602 million.

Health Careers Opportunity Program.—Grants made to health professions schools and educational entities under HCOP enhance the ability of individuals from disadvantaged backgrounds to improve their competitiveness to enter and graduate from health professions schools. HCOP funds activities that are designed to develop a more competitive applicant pool through partnerships with institutions of higher education, school districts, and other community based entities. HCOP also provides for mentoring, counseling, primary care exposure activities, and information regarding careers in a primary care discipline. Sources of financial aid are provided to students as well as assistance in entering into health professions schools. For fiscal year 2014, the HCOP funding level of \$22.133 million is recommended.

NATIONAL INSTITUTES OF HEALTH

National Institute on Minority Health and Health Disparities.—The NIMHD is charged with addressing the longstanding health status gap between under-represented minority and non minority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, telemedicine technology and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and developed a comprehensive plan for research on minority health at NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through the COE program and HCOP. For fiscal year 2014, an increase proportional to NIH's increase is recommended for NIMHD as well as additional FTEs.

Research Centers at Minority Institutions.—RCMI, now at NIMHD, has a long and distinguished record of helping institutions like The Charles Drew University develop the research infrastructure necessary to be leaders in the area of translational research focused on reducing health disparities research. Although NIH has received some budget increases over the last 5 years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2014.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities, supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions. For fiscal year 2014, I recommend a funding level of \$65 million for OMH to support these critical activities. Additionally, I recommend that this Committee ensures that OMH continues with its grant-making authority, as this is one of the chief avenues by which it is able to impact the scourge of disparities in our communities.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions.—The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to CDU and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2014, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

CONCLUSION

Despite all the knowledge that exists about racial/ethnic, socio-cultural and gender-based disparities in health outcomes, the gap continues to widen. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventative care and research are inaccessible either due to distance or lack of facilities and expertise. As noted earlier, in just one underserved area, South Los Angeles, the number and distribution of beds, doctors, nurses and other health professionals are as parlous as they were at the time of the Watts Rebellion, after which the McCone Commission attributed the so-named 'Los Angeles Riots' to poor services—particularly access to affordable, quality healthcare. The Charles Drew University has proven that it can produce excellent health professionals who 'get' the mission—years after graduation they remain committed to serving people in the most need. But, the university needs investment and committed increased support from Federal, State and local governments and is actively seeking foundation, philanthropic and corporate support.

Even though institutions like The Charles Drew University are ideally situated (by location, population, community linkages and mission) to study conditions in which health disparities have been well documented, research is limited by the paucity of appropriate research facilities. With your help, the Life Sciences Research Facility will translate insight gained through research into greater understanding of disparities and improved clinical outcomes. Additionally, programs like Title VII Health Professions Training programs will help strengthen and staff facilities like our Life Sciences Research Facility.

We look forward to working with you to lessen the huge negative impact of health disparities on our Nation's increasingly diverse populations, the economy and the whole American community.

Mr. Chairman, thank you again for the opportunity to present testimony on behalf of the Charles Drew University. It is indeed an honor.

PREPARED STATEMENT OF THE CHILDREN'S ENVIRONMENTAL HEALTH NETWORK

We thank Chairman Reed and Ranking Member Murkowski for this opportunity and for your ongoing concern about environmental health risks to children. Our statement focuses on key programs and activities that safeguard the health and the future of all of our children. Today we are addressing activities of two agencies that are critical to children's environmental health and are within the subcommittee's jurisdiction:

- Centers for Disease Control and Prevention, especially the National Center for Environmental Health/Agency for Toxic Substances and Disease Registry and related programs:
 - Healthy Homes and Lead Poisoning Prevention Program
 - National Asthma Control Program
 - National Environmental Public Health Tracking Program
 - Environmental Health Laboratory
 - Healthy Community Design Initiative (HCDI)
 - Pediatric Environmental Health Specialty Units (PEHSUs)
- National Institute of Environmental Health Sciences (NIEHS), an Institute of the National Institutes of Health (NIH) that has as its mission discovering how the environment affects people in order to promote healthier lives. CEHN is especially interested in NIEHS' Children's Environmental Health Research Centers of Excellence.

The Children's Environmental Health Network (CEHN) is a national organization created to protect the developing child from environmental health hazards and promote a healthy environment.

Investments in programs that protect and promote children's health will be repaid by healthier children with brighter futures. For example, removing lead in gasoline has saved the U.S. an estimated \$200 billion each year since 1980 in the form of higher IQs for that year's newborns. Protecting our children—those born as well as those yet to be born—from environmental hazards is truly a national security issue.

Our Nation's future will depend upon its future leaders. When we protect children from harmful chemicals in their environment, we help to assure that they will reach their full potential. We have a responsibility to our Nation's children, and to the Nation that they will someday lead, to provide them with a healthy environment. Additionally, American competitiveness depends on having healthy educated children who grow up to be healthy productive adults. Yet, growing numbers of our children are diagnosed with chronic and developmental illnesses and disabilities such as obesity,

asthma, learning disabilities, and autism. A child's environment plays a role in these chronic conditions and contributes to the distressing possibility that today's children may be the first generation to see a shorter life expectancy than their parents due to poor health. Thus it is vital that the Federal programs and activities that protect children from environmental hazards receive adequate resources.

We strongly urge the Committee to take a balanced approach to deficit reduction that does not include further cuts to children's environmental health programs. Key programs in your jurisdiction, which CEHN urges you to support, include:

Centers for Disease Control and Prevention (CDC).—As the Nation's leader in public health promotion and disease prevention, the CDC should receive top priority in Federal funding. CDC continues to be faced with unprecedented challenges and responsibilities. CEHN applauds your support for CDC in past years and urges you to support a funding level of \$7.8 billion for CDC's core programs in fiscal year 2014.

The National Center for Environmental Health (NCEH) is particularly important to protecting the environmental health of young children. NCEH's programs are key national assets. Yet, since fiscal year 2009, NCEH funding has been cut approximately 25 percent while, as mentioned above, environment plays a role in the cause, prevention, or mitigation of today's pediatric epidemics of obesity, asthma, learning disabilities, and autism.

Agency for Toxic Substances and Disease Registry (ATSDR).—CEHN urges the subcommittee to provide funding at or above the requested levels for ATSDR activities. ATSDR uses the best science in taking public health actions, such as site assessments and toxicological profiles, to prevent harmful exposures and diseases of communities and individuals related to toxic substances.

ATSDR understands that in communities faced with contamination of their water, soil, air, or food, infants and children can be more sensitive to environmental exposure than adults and that assessment, prevention, and efforts to find remedies for exposures must focus on children because of their vulnerability and importance to the Nation's future. We support the full funding of ATSDR and the continuation of their varied responsibilities.

We continue to be concerned about the elimination of Healthy Homes and Lead Poisoning Prevention Program funding for State and local programs in fiscal year 2012. The loss of vigilant surveillance, primary prevention activities, and case management has jeopardized the health of children living in homes where exposure to lead, asthma and other illnesses related to rodent and insect infestation, chemical exposures, and other risk factors is likely. We must sustain reducing lead poisoning by supporting effective local and State efforts.

NCEH's National Asthma Control Program funds 36 States and territories to conduct asthma surveillance, educate asthma patients, families, and health care providers, and help health departments eliminate potential asthma triggers. Now is the time to maintain our commitment to asthma control, not cut funding.

The CDC's National Environmental Public Health Tracking Program helps to track environmental hazards and the diseases they may cause and to coordinate and integrate local, State and Federal health agencies' collection of critical health and environmental data. Public health officials need integrated health and environmental data so that they can protect the public's health. This network currently operates in 23 States and New York City to help public health officials and key policymakers make better policy decisions to improve population health. Participation in the tracking network development will decline further under any further cuts and erase the progress we have made across the country to better link data with public health action.

Pediatric Environmental Health Specialty Units.—Funded jointly by the Agency for Toxic Substances and Disease Registry (ATSDR) and the EPA, the Pediatric Environmental Health Specialty Units (PEHSUs) form a valuable resource network, with a center in each of the U.S. Federal regions. PEHSU professionals provide medical consultation to health care professionals on a wide range of environmental health issues, from individual cases of exposure to advice regarding large-scale community issues. PEHSUs also provide information and resources to school, child care, health and medical, and community groups to help increase the public's understanding of children's environmental health, and help inform policymakers by providing data and background on local or regional environmental health issues and implications for specific populations or areas. We urge the subcommittee to fully fund this program in fiscal year 2014.

CEHN also strongly supports CDC's Environmental Health Laboratory and the Healthy Community Design Initiative (HCDI). The HCDI provides essential expert assistance and consultation across HHS and national leadership on the impacts of the built environment on health including physical activity levels.

National Institute of Environmental Health Science (NIEHS).—NIEHS is the leading institute conducting research to understand how the environment influences the development and progression of human disease. NIEHS plays a vital role in our efforts to understand how to protect children, whether it is identifying and understanding the impact of substances that are endocrine disruptors or understanding childhood exposures that may not affect health until decades later. CEHN recommends that \$717.7 million be provided for NIEHS' fiscal year 2014 budget.

Children's Environmental Health Research Centers of Excellence.—The Children's Environmental Health Research Centers, jointly funded by the NIEHS and the U.S. Environmental Protection Agency (EPA), play a key role in providing the scientific basis for protecting children from environmental hazards. With their modest budgets, which have been unchanged for more than 10 years, these centers generate valuable research. The scientific output of these centers has been outstanding. Several Centers have established longitudinal cohorts, which have resulted in valuable research results. The Network is concerned that as a Center's multi-year grant ends and the Center is shuttered, these cohorts and the invaluable information they can provide are being lost. The Network urges the subcommittee to assure that NIEHS has the funding and the direction to support Centers in continuing these cohorts. The work of these Centers has also shown us that, in addition to research regarding a specific pollutant or health outcome, research is desperately needed in understanding the totality of the child's environment—for example, all of the exposures the child experiences in the home, school, and child care environment—and how to evaluate those multiple factors. CEHN urges you to support these Centers to assure they receive full funding and are extended and expanded as described above.

In conclusion, healthier children with brighter futures will repay investments in programs that protect and promote children's health, an outcome we can all support. Thank you for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE COALITION OF EPSCoR/IDEA STATES

Mr. Chairman and members of the subcommittee; thank you for the opportunity to submit this statement regarding fiscal year 2014 funding for the National Institutes of Health's Institutional Development Award or "IDEA" Program. The IDEA program is supported by NIH's National Institute of General Medical Sciences (NIGMS), and was authorized by the 1993 NIH Revitalization Act (Public Law 103–43). I submit this testimony on behalf of the Coalition of EPSCoR/IDEA States¹ and LSU, and respectfully request that this committee recommend that the IDEA program be funded in fiscal year 2014 at \$310 million.

The National Institutes of Health's (NIH) Institutional Development Award Program (IDEA) was established in 1993 to broaden the geographic distribution of NIH funding for biomedical and behavioral research. The IDEA program funds only merit-based, peer-reviewed research that meets NIH research objectives. The program fosters health-related research and enhances the competitiveness of investigators at institutions in 23 States and Puerto Rico. The program also serves unique populations, such as rural and medically underserved communities, in these States. The IDEA program has two key components: Centers of Biomedical Research Excellence (COBRE) and IDEA Networks of Biomedical Research Excellence (INBRE). COBRE programs build multi-disciplinary research centers with a thematic scientific focus. Junior investigators graduate from the program after they obtain NIH competitive funding on their own. INBRE programs enhance biomedical research capacity in primarily undergraduate institutions in alliance with LSU, as a major research institution in Louisiana. These two programs play complementary roles in developing research capability and human capital in biomedical fields in Louisiana and the rest of the IDEA States.

Impact of the IDEA Program on Louisiana

Louisiana leads all the EPSCoR/IDEA States in successfully competing for COBRE and INBRE grants. Ten different COBRE grants and one INBRE Center grant have been funded in the last 10 years totaling more than \$200 million dollars. The Louisiana INBRE is led by the LSU in Baton Rouge as the flagship institution, which coordinates the training of scientists from a number of primarily undergraduate in-

¹ Alabama, Alaska, Arkansas, Delaware, Hawaii, Idaho, Iowa, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Puerto Rico, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, West Virginia, and Wyoming.

States in italic letters are eligible for the IDEA program. All of the States listed above are also eligible for the EPSCoR program.

stitutions in Louisiana such as the University of Louisiana in Monroe, LSU-Shreveport, Southern University in Baton Rouge, Xavier University in New Orleans, and Louisiana-Tech University in Ruston. All other Louisiana universities participate in the INBRE program through the summer research program. These students and faculty are trained at major research facilities around the State including: LSU, Pennington Biomedical Research Center, Tulane Medical Center in New Orleans, and the LSU Health Sciences Centers in New Orleans and Shreveport. The INBRE program provides opportunities via collaboration with all Louisiana-based COBRE programs, therefore creating a highly regarded network of life scientists throughout Louisiana.

The Louisiana success in COBRE funding has been focused on highly important areas of research of particular significance to the health of the citizens of Louisiana. These research areas include: (1) obesity and cardiovascular health (COBREs at Pennington Biomedical Research Center in Baton Rouge, LSU Health Sciences Center in New Orleans, and Tulane University in New Orleans); (2) cancer research (COBREs at Tulane University and LSU Health Sciences Center in Shreveport); (3) neurosciences (COBRE at LSU Health Sciences in New Orleans); (4) infectious disease research (COBRE at the LSU School of Veterinary Medicine and Tulane National Primate Research Center); (5) obesity and diabetes (COBRE at Pennington Biomedical Research Center in Baton Rouge); (6) aging research (COBRE at Tulane University); and (7) oral health (COBRE at the LSU School of Dentistry in New Orleans). Recently, special COBRE funding was awarded to Louisiana for the establishment of the Louisiana Clinical & Translational Science Center (LACaTS) involving all biomedical research and medical training programs in Louisiana working together to translate research findings to improve clinical care. Specifically, this collaborative network of scientists and clinicians focuses on the prevention, care and research of chronic diseases in the underserved population of Louisiana and the Nation. This COBRE Clinical and Translational Research award (COBRE-CTR) is led by the Pennington Biomedical Research Center in Baton Rouge.

The COBRE and INBRE Project grants require the presence of senior mentors for junior investigators including students, postdoctoral fellows and junior faculty. The COBRE and INBRE funding has been a key factor in the retention of well-funded investigators serving as principal investigators or mentors in each program.

Total economic impact for Louisiana stemming from the IDeA program is approximately \$300 million, when taking into account the presence of senior researchers that have been retained in Louisiana. This amounts to a total economic impact of \$600 million based on an economic impact multiplier of 2. Importantly, the IDeA funding has enabled the formation of a Louisiana-wide network of life scientists, opening up new collaborations and unsurpassed training opportunities for all students and faculty. The Louisiana Optical Network Initiative (LONI), funded by State funds, has enabled direct connectivity and communication among all COBRE and INBRE recipients through the INBRE-led access grid network; allowing remote training, sharing of seminar speakers and other training functions across Louisiana. IDeA funding has impacted the teaching and training of more than 1000 researchers and students in Louisiana.

While IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103-43), sizable increases in funding only began in fiscal year 2000. The program then grew rapidly, due in large part to the thoughtful actions of this subcommittee. This funding permitted the initiation of the COBRE and INBRE, which have been crucial to the success of the program. On behalf of the Coalition and LSU, I want to express gratitude to this subcommittee for the efforts it has made over the years to provide increased funding for IDeA, in particular this committee's work to ensure the successful inclusion of a \$50 million increase for the program in fiscal year 2012. I hope that you will continue to invest in this program, which is so important to almost half of the States in the Union.

We request that this committee recommend the IDeA program be funded in fiscal year 2014 at \$310 million. As you know, the EPSCoR/IDeA Coalition has maintained that IDeA program should constitute at least 1 percent of the total NIH budget. This level of funding would restore and continue funding for COBRE and INBRE, provide funding for the COBRE Clinical and Translational Research (CTR) program, and provide for co-funding opportunities which allow researchers and institutions to merge with the overall national biomedical research community.

Over 22 percent of the Nation's population live in the EPSCoR/IDeA States, yet in fiscal year 1999, the year before COBRE grants were initiated, the 23 IDeA States and Puerto Rico received a total of \$596 million from NIH. And that is why the IDeA program is so important. It is helping to ensure that all regions of the country participate in biomedical research and education. Citizens from all States

should have the opportunity to benefit from the latest innovations in health care, which are most readily available in centers of biomedical research excellence.

To put the value of the IDeA investment into perspective, the overall fiscal year 2012 IDeA budget, \$276.48 million, is only 42 percent of the \$645.3 million in NIH funding that Johns Hopkins University alone, in a non-IDEA State, received in fiscal year 2011. In fiscal year 2011, the top seven States with NIH funding received over a \$1 billion each, and California alone received over \$3.5 billion. Given this, \$310 million for 23 States and Puerto Rico seems more than reasonable.

On behalf of the EPSCoR/IDEA Coalition, LSU and our partner institutions across Louisiana, I thank the subcommittee for the opportunity to submit this testimony.

PREPARED STATEMENT OF THE COALITION FOR USHER SYNDROME RESEARCH

PARENT OF 12 YEAR OLD TWINS WITH USHER SYNDROME, PARENT ADVOCATE REPRESENTING THE COALITION FOR USHER SYNDROME RESEARCH AND INDIVIDUALS WITH USHER SYNDROME

My name is Susie Trotochaud from the State of Georgia. I submit testimony on behalf of the Coalition for Usher Syndrome Research to respectfully request this committee encourage NIH funding of \$20 million in fiscal year 2014 to promote more research into Usher Syndrome.

Usher Syndrome is the number one cause of deaf-blindness. Deaf-Blindness. Imagine being unable to hear my words and unable to see me. Silence and darkness. In the United States, it is estimated that about 45,000 people have this rare genetic disorder. Two of them are my children, Cory and Joanie Dorfman.

Cory and Joanie were born 8 weeks early. Although they spent several weeks in ICU fighting to learn basic survival skills, like breathing and eating, these would not be their greatest challenges. Before they were released from the hospital, they were given a newborn hearing screening. It was determined that they were both profoundly deaf. As we struggled to understand what this meant and how this could have happened, I realized that they would never be able to hear me say "I love you" and I would never hear those sweet words from their lips. The sounds of our life, children laughing, singing, school plays, graduations, celebrations, were suddenly silenced.

Our heartache changed to hope when we found out about the cochlear implant. By 12 months, Cory and Joanie were implanted and began hearing their first sounds. By 1-1/2 years, they had said their first words, and by 3 years, we realized that they could be mainstreamed, go on through high school and even college, just like their peers. Although they would always have to work a little harder, the sounds of opportunity returned to our lives. And I remember my husband saying to me at that time, "At least they're not blind."

But about a year ago, that all changed. After my daughter entered a darkened hallway in a restaurant and asked me where the bathroom was, when the door was literally four feet in front of her, we became concerned. When she gingerly stepped down a pathway at night, seemingly feeling her way with her feet, we knew we had a problem. Many months of extensive testing and waiting confirmed what we, by then, already knew. Joanie had Type I Usher Syndrome. Reading the description of Type I Usher was like reading her biography: Born profoundly deaf, delayed development especially walking, balance issues, and loss of night vision beginning at around 10 years of age. What would follow would be loss of peripheral vision leading to tunnel vision, and eventually blindness. With no intervention, my 12 year old daughter will be blind by 20. And although my son currently has less vision issues, testing confirms he also has Usher. He may retain some of his vision into his 30s.

That's the thing with Usher. It strikes in varying timeframes. Type I, like with my children, is characterized by profound deafness at birth followed by blindness in early adolescence; Type II individuals may have moderate to severe hearing loss followed by blindness; and Type III experience loss of hearing and sight throughout their lives. How quickly and how completely each person loses their vision also varies, but the way it happens is consistent. Night blindness, then peripheral vision is lost as darkness closes in on their sight. Usher is a rollercoaster ride of loss, grief, adjustment, and loss again that never ends as one more setback always lies around the corner.

People with Usher Syndrome, like Cory and Joanie, have worked hard to overcome some of their hearing challenges by using cochlear implants, hearing aids, sign language and more. But how do you overcome the loss of sight? Think of yourself, sitting here communicating by sign, knowing that you are losing your vision, know-

ing you are about to lose your way of communicating with the world around you. Frightening, isn't it?

Like you, my hopes and dreams for my children have always been that they grow up happy, do well in school, attend good colleges, get meaningful jobs and give back to their community. But the reality we are facing is that 8 out of 10 deaf-blind people are unemployed, not to mention the physical and emotional hardships, the stereotypes of being deaf-blind, the loss of productivity and ability to do a job, ultimate depression, and perhaps even suicide.

Add to that the reality that our country spends an estimated \$27 billion annually in care and support services for people with major visual disorders. That doesn't even include the costs associated with hearing impairment.

Those are statistics; people with Usher aren't. Since joining the Coalition for Usher Syndrome Research, I have spoken with or met dozens of people who are determined, focused, and working every day to help themselves, their loved one, or in some cases complete strangers, figure out how to treat this syndrome. Usher genes are complex, long protein cells which require significant investment in research if we are ever to find a cure or treatment. We can't do it alone.

Through the Coalition, we have brought the Usher community and researchers together by:

- Establishing a registry of individuals with Usher Syndrome which is available for research or clinical trials at no cost. Our registry currently has families from each of the 50 States and 23 countries.
- Sponsoring annual family conferences, webinars and monthly conferences that provide information and support to all of those living with Usher.
- Paving the way for an International Symposium on Usher Syndrome Research in 2014 to develop a roadmap for future research projects to bring us closer to viable clinical trials.

With this in place, we have begun bringing brilliant researchers together who are working on developing treatments every day. Researchers like those in Oregon and Pennsylvania who are working on gene therapy treatments, one of which began clinical trials this year. Researchers in Louisiana, who have been able to rescue the hearing in mice with Usher Syndrome using a drug therapy that holds promise for rescuing vision, as well. Researchers in Iowa, California, Nebraska, Massachusetts, Florida, Texas, and many other States, who are collaborating with each other and with families through the Coalition to advance all kinds of Usher syndrome research.

But still this is not enough. My daughter, Joanie, will be blind within 10 years; my son, Cory, in 20. Jessica, a 17-year old with Usher, remains hopeful that something will help her retain her vision before she loses it at 30. Megan, a promising architect, has already altered her career goals as her vision has begun to slowly fade and every day she prays for something to help. Moira has lived well into her adult life working harder than everyone else to compete in a hearing and seeing world, but complete blindness is now taking away her ability to lip read and communicate with her friends and family.

We cannot help any of these people or the tens of thousands who have Usher or countless others that will be born in the future with this devastating genetic disorder without Federal support. There are dozens of different mutations that cause Usher Syndrome and the pace of research is slowed dramatically by the lack of researchers and funding. The infrastructure is there to find treatments, but the significant financial support is not. We believe that \$20 million in support this year and an increase of that amount over the next several years would lead to viable treatments for those with Usher Syndrome within a decade. We are asking you to supply this last critical resource to help us find a cure.

When you review the report on categorical spending by the NIH, Usher Syndrome is not even listed. Rare diseases with similar incident rates average around \$50 million annually. These investments have resulted in significant discoveries for these diseases, and there is reason to believe that we can see these same results or better for Usher Syndrome. The researchers are there, waiting to discover what we only dare dream of: An opportunity to allow deaf children and adults who are going blind, a chance to see.

I will leave you with the words of Helen Keller. "It is a terrible thing to see, but have no vision." I hope that this committee will have the vision to see the opportunities before them. Together, we can find a way to end deaf-blindness. I thank you on behalf of all those with Usher Syndrome, their families, and most importantly to me, my children, Cory and Joanie.

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

As the subcommittee begins to develop the fiscal year 2014 Labor, Health and Human Services, Education, and Related Agencies appropriations bill, the Coalition of Northeastern Governors (CONEG) urges you to fund the Low Income Home Energy Assistance Program (LIHEAP) at the authorized level of \$5.1 billion but no less than \$4.7 billion in the core block grant program. The Governors appreciate the subcommittee's continued support for LIHEAP, and recognize the difficult fiscal challenges facing Congress this year. However, the economic challenges facing the Nation's low-income households have made this program more essential than ever. Adequate, predictable and timely Federal funding is vital for LIHEAP to assist the vulnerable, low-income households who struggle to pay increased home energy bills. Therefore, we urge the subcommittee to provide the fiscal year 2014 funds in a manner consistent with the LIHEAP statutory objective: "to assist low-income households, particularly those with the lowest incomes that pay a high proportion of household income for home energy, primarily in meeting their immediate home energy needs.

LIHEAP is a vital safety net for the most vulnerable citizens in every region of the Nation: the elderly, disabled, and families with young children struggling to pay for the basic necessity of home energy. According to the National Energy Assistance Directors' Association (NEADA), 8.9 million households received heating and cooling assistance in fiscal year 2012. Nationwide, the majority of LIHEAP households have at least one member defined as "vulnerable," and many of these households are not likely to benefit from the modest improvements in national economic and employment patterns. Moreover, approximately 20 percent of LIHEAP households contain at least one member who served this country in the military. LIHEAP is a resource that States across the country are able to use to assist vulnerable households in paying a portion of their heating bills in the cold winter months and a portion of their electricity bills for cooling in the hot months.

Households in the Northeast face some of the Nation's highest home heating bills due to the extended winter heating season and heating fuel prices that typically exceed national averages regardless of the fuel used. Recent trends in residential heating fuel prices suggest that low-income households in the Northeast will continue to experience a heavy energy burden. According to the recent Energy Information Administration (EIA) Winter Fuels Outlook, Northeast households are more likely to face higher natural gas prices than other regions of the Nation. While delivered fuels, such as heating oil and propane, are used nationwide, Northeast households—more than any other region of the country—are dependent upon these expensive delivered fuels, particularly in the many areas where there is limited or no access to natural gas service. In the Northeast, 30 percent of households rely upon delivered fuels, and they account for approximately 80 percent of the homes nationwide that use home heating oil. When prices rise, these households are particularly vulnerable. Low-income households that use delivered fuels are less likely to have the option of payment plans, access to utility assistance programs, and the protection of utility service shut-off moratoria during the heating season. If LIHEAP funds are not available to these households, the fuel delivery truck simply does not come.

According to EIA's current data, residential heating oil prices have been stable over the past two heating seasons, but at the historically high average price of approximately \$4.00 per gallon—a price that is almost 30 percent higher than the five year average price. At this price, and with the more typical winter temperatures experienced by the region, EIA anticipates that expenditures for heating oil this heating season could increase by 32 percent from last winter. In the past 2 years, the average price of residential heating oil in the Northeast has increased 43 percent—from an average of \$2.89 per gallon in February 2010 to an average of \$4.15 per gallon in February 2013. During the same period, the annual LIHEAP funding level has declined by 30 percent—from \$5.1 billion in fiscal year 2010 to approximately \$3.3 billion in fiscal year 2013.

LIHEAP is the foundation of efforts to provide immediate, meaningful assistance to low-income households, many living on modest, fixed incomes. Most LIHEAP assistance is targeted to households whose income is close to or below 150 percent of the Federal poverty level, which for a two-person household is \$23,265 in 2013. These households spend a disproportionate amount of their income on home energy, often over three times more than non-low-income households. LIHEAP not only helps households better manage and pay home energy bills, it protects the health and safety of the elderly, young children and the disabled. Without adequate resources to pay home heating bills, these vulnerable households may resort to unsafe and dangerous heating sources such as ovens and space heaters. In the summer, these populations are particularly susceptible to heat-related illness and even death.

While LIHEAP funding has been reduced by more than 30 percent since fiscal year 2010, the need for the program continues to grow nationwide. States have faced significant challenges in trying to stretch scarce LIHEAP dollars as far as possible while still providing a meaningful benefit to those households most in need of assistance. States have worked with utilities to develop payment plans to reduce arrearages and lessen the prospect of utility shut-offs after the heating season ends. They have negotiated with fuel dealers to receive discounts on deliverable fuels, and have entered into agreements to purchase fuel in the summer when prices are lowest. Some Northeast States have also stretched their own limited budgets to provide supplemental LIHEAP funds or to leverage Federal dollars. Even after taking significant cost-cutting steps, States have had to take actions such as tightening program eligibility, closing the program early, and reducing benefit levels. The most recent funding reductions, coming as the heating season winds down and utility shut-off moratoriums expire, have created additional challenges. The potential result is a loss of funding for benefits to pay down arrearages, as well as inadequate staff to assist those households facing utility shut-offs to find alternative arrangements.

In summary, the CONEG governors appreciate the subcommittee's continued support for LIHEAP, and urge you to fund the program at the authorized level of \$5.1 billion but no less than \$4.7 billion in the core block grant program for fiscal year 2014.

PREPARED STATEMENT OF THE COLLEGE OF VETERINARY MEDICINE, NURSING &
ALLIED HEALTH

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) Title VII Health Professions Training Programs:
 - \$24.602 million for the Minority Centers of Excellence.
 - \$22.133 million for the Health Careers Opportunity Program.
 - 2) Increased support for the National Institutes of Health's National Institute on Minority Health and Health Disparities.
 - 3) \$32 billion for the National Institutes of Health.
 - Proportional funding increase for the National Institute on Minority Health and Health Disparities.
 - Proportional funding for Research Centers for Minority Institutions.
 - 4) \$65 million for the Department of Health and Human Services' Office of Minority Health.
 - 5) \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.
-

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Tsegaye Habtemariam, dean of the College of Veterinary Medicine, Nursing, and Allied Health at Tuskegee University. The mission (purpose) of Research and Advanced Studies at the College of Veterinary Medicine, Nursing & Allied Health (CVMNAH) is to transform trainees into ambassadors of the Tuskegee tradition to benefit Man and animals. Such a tradition is honed in the "one medicine-one health" concept that for decades has guided our academic mission, to expand biosciences and create bridges between veterinary medicine, agricultural and food sciences on one side and human health and welfare on the other.

Mr. Chairman, I speak for our institutions, when I say that the minority health professions institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, even after the landmark passage of health reform, it is important to note that our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help Tuskegee continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to

produce healthcare professionals committed to addressing this unmet need—even in austere financial times.

An October 2006 study by the Health Resources and Services Administration (HRSA)—during the Bush Administration—entitled “The Rationale for Diversity in the Health Professions: A Review of the Evidence” found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation’s healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

In fiscal year 2014, funding for the Title VII Health Professions Training programs must be robust, especially the funding for the Minority Centers of Excellence (COEs) and Health Careers Opportunity Program (HCOPs). In addition, the funding for the National Institutes of Health (NIH)’s National Institute on Minority Health and Health Disparities (NIMHD), as well as the Department of Health and Human Services (HHS)’s Office of Minority Health (OMH), should be preserved.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions to the training of minorities in the health professions. Congress later went on to authorize the establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. For fiscal year 2014, I recommend a funding level of \$24.602 million for COEs. Additionally, I encourage the Committee direct HRSA to re-evaluate the funding mechanism for the original four COEs, as it does not always lead to funding based on the merit of an institution’s proposal.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional. For fiscal year 2014, I recommend a funding level of \$22.133 million for HCOPs.

NATIONAL INSTITUTES OF HEALTH

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professions institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities through its Centers of Excellence program. For fiscal year 2014, I recommend funded increases proportional with the funding of the overall NIH, with increased FTEs.

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI), newly moved to the National Institute on Minority Health and Health Disparities has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget in-

creases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2014.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health.—Specific programs at OMH include: assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals; assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers; supporting conferences for high school and undergraduate students to interest them in health careers, and supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, but that role is only possible if this agency continues to keep its grant-making authority. For fiscal year 2014, I recommend a funding level of \$65 million for the OMH.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions.—The Department of Education's Strengthening Historically Black Graduate Institutions (HBGI) program (Title III, Part B, Section 326) is extremely important to AMHPS. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2014, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Tuskegee University's College of Veterinary Medicine, Nursing, and Allied Health, Title VII Health Professions Training programs and the historically black health professions schools can help this country to overcome health disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. CVMNAH seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman.

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Mr. Chairman and members of the subcommittee, thank you for the opportunity to submit testimony to the subcommittee in support of the National Institute on Drug Abuse. The College on Problems of Drug Dependence (CPDD), a membership organization with over 800 members, has been in existence since 1929. It is the longest standing group in the United States addressing problems of drug dependence and abuse. The organization serves as an interface among governmental, industrial and academic communities maintaining liaisons with regulatory and research agencies as well as educational, treatment, and prevention facilities in the drug abuse field. CPDD also often works in collaboration with the World Health Organization.

Recognizing that so many health research issues are inter-related, CPDD requests that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH). Because of the critical importance of drug abuse research for the health and economy of our Nation, we also request that you provide a proportionate increase for the National Institute on Drug Abuse in your Fiscal 2014 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease—this new knowledge has helped to correctly situate drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug use—over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern, such as prescription drug abuse, remain and we support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2014 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE CONSORTIUM OF SOCIAL SCIENCE ASSOCIATIONS

Mr. Chairman and members of the subcommittee: The Consortium of Social Science Associations (COSSA) welcomes the opportunity to comment on the fiscal year 2014 Appropriations for the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ).

COSSA is an advocacy group for the social and behavioral sciences supported by 115 professional associations, scientific societies, universities and research centers. COSSA serves as a bridge between the academic research and Washington policy-making community. Our organizations are appreciative of the subcommittee's and the Congress' continued support of the NIH, CDC, and AHRQ. Strong, sustained funding is essential to the national priorities of better health and economic revitalization.

COSSA joins the Ad Hoc Group for Medical Research in requesting a minimum appropriation of \$32 billion for NIH for fiscal year 2014. As a member of the CDC Coalition, COSSA requests \$7.8 billion in funding for CDC in fiscal year 2014. Lastly, we join the Friends of AHRQ in recommending a funding level of \$181.5 million for AHRQ in fiscal year 2014.

Social and Behavioral Science Research at the National Institutes of Health

As this Committee knows, the mission of the NIH is to support scientifically rigorous, peer/merit-reviewed, investigator-initiated research, including basic and applied behavioral and social science research. The fundamental understanding of how disease works, including the impact of social environment on these disease processes, underpins our ability to conquer devastating illnesses. And while Americans have achieved very high levels of health over the past century and are healthier than people in many other nations, according to the recently released National Academies' report, *U.S. Health in International Perspective: Shorter Lives, Poorer Health*, "a growing body of research suggests that the health of the U.S. population is not keeping pace with the health of people in other economically advanced, high-income countries."

The behavioral and social sciences make important contributions to the well-being of this Nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous role behavior plays in our health. Though we have made enormous progress toward achieving genetic control over disease, knowledge of the behavioral influences on health will always be a crucial component in our battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness.

As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning. This includes NIH's support of economic research, specifically, research on the linkages between socioeconomic status and health outcomes in the elderly and achievement and health outcomes in children. This research has been an integral part of the interdisciplinary science NIH has historically supported. Accordingly, the agency's investment has yielded key data, methodologies and substantive insights on some of the most important and pressing issues facing the U.S. For example, NIH-funded surveys such as the Health and Retirement Survey, the Panel Study of Income Dynamics (PSID), parts of the National Longitudinal Survey of Labor Market Experiences, and surveys on international aging and retirement provide data necessary to monitor and detect changes in important socioeconomic trends in health. This in turn allows NIH to support research that will provide the greatest return on its investment when it comes to the health of our citizens.

Social and behavioral scientists have made significant strides in shedding light on the basic social and cultural structures and processes that influence health. Social and cultural factors influence health by affecting exposure and vulnerability to disease, risk-taking behaviors, the effectiveness of health promotion efforts, and access to, availability of, and quality of health care. Social and cultural factors also play a role in shaping perceptions of and responses to health problems and the impact of poor health on individuals' lives and well-being. In addition, such factors contribute to understanding societal and population processes such as current and changing rates of morbidity, survival, and mortality.

Despite the dramatic contributions that behavioral and social science research has made to date, much more remains to be understood in the role behavioral and social factors play in disease and how to use that knowledge to improve the Nation's health. Breakthroughs in the behavioral and social sciences over the next 20 years will be critical to addressing our most pressing public health challenges and transforming health care.

The application of the results of basic research to the detection, diagnosis, treatment and prevention of disease is the ultimate goal of medical research. Ensuring a steady pipeline of basic research discoveries while also supporting the translational efforts necessary to bring the promise of this knowledge to fruition requires a sustained investment in NIH.

Social and Behavioral Science Research at the Centers for Disease Control and Prevention

As the country's leading health protection and surveillance agency, the CDC works with State, local, and international partners to protect Americans from infectious diseases; prevent the leading causes of disease, disability, and death; protect Americans from natural and bioterrorism threats; monitor health and ensure laboratory excellence; keep Americans safe from environmental and work-related hazard; and ensure global disease protection. To cite just one example of the enormous strides the CDC is making in keeping America and the world safe from disease, with adequate investment, the CDC expects to stop all wild poliovirus transmissions by the end of 2014, as part of the Global Polio Eradication Initiative.

Social and behavioral science plays a crucial role in helping the CDC carry out its mission. Scientists from fields ranging from psychology, sociology, anthropology, and geography to health communications, social work, and demography work in every CDC Center to design, analyze, and evaluate behavioral surveillance systems, public health interventions, and health promotion and communication programs using a variety of both quantitative and qualitative methods.

These scientists play a key role in the CDC's surveillance and monitoring efforts, which collect and analyze data to better target public health prevention efforts. For example, the Behavioral Risk Factor Surveillance System, which collects data about Americans' health-related risk behaviors and events, chronic health conditions, and

use of preventive services, is used to establish and track State and local health objectives, plan health programs, implement disease prevention and health promotion activities, and monitor trends.

Another vital contribution of the social and behavioral sciences to CDC activities is in identifying and understanding health disparities. Although the overall health of Americans has improved over the last decades, differences in health based on race, ethnicity, gender, income, geographical location, education level, disability status, and sexual orientation persist. Rigorous, cross-disciplinary efforts are needed to develop effective interventions to reduce these entrenched disparities and inequities.

The social and behavioral sciences play an important role in the evaluation of CDC programs. When programs conduct strong, practical evaluations on a routine basis, the findings are better positioned to inform their management and improve program effectiveness. Evaluating public health programs tells us what is and isn't working and can help policymakers make informed, evidence-based decisions on how to prioritize in a resource-scarce environment.

The CDC is the home of the Nation's principal health statistics agency, the National Center for Health Statistics (NCHS). NCHS collects data on chronic disease prevalence, health care disparities, emergency room use, teen pregnancy, infant mortality, causes of death and rates of insurance, to name a few. It provides critical data on all aspects of our health care system through data cooperatives and surveys that serve as the gold standard for data collection around the world. Data from NCHS surveys like the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES) and the National Vital Statistics System (NVSS) are used by agencies across the Federal Government, State and local governments, public health officials, Federal policymakers, and demographers, epidemiologists, health services researchers, and other scientists.

Health Services Research at the Agency for Healthcare Research and Quality

AHRQ's sole purpose is to improve health care in America. Just as biomedical research helps us find cures for disease, the health services research AHRQ supports helps find ways to cure our health care system—improving its quality, safety, and efficiency for the benefit of patients. AHRQ's research identifies what works and what doesn't in health care to improve patient care and provide policymakers and other health care leaders with the information needed to make critical health care decisions.

AHRQ helps providers help patients. Americans want to take personal responsibility for their health, and they rely on their doctors, nurses, pharmacists and other health care providers for guidance in making difficult choices. AHRQ's research generates valuable evidence to help providers help patients make the right health care decisions for themselves and their loved ones. For example, the American College of Physicians used AHRQ-funded research to inform their recommendations for treatment of type 2 diabetes. These evidence-informed recommendations give physicians a foundation for describing what the best care looks like, so patients can determine what the right care might be for them.

AHRQ is keeping patients safe. The science funded by AHRQ ensures patients receive high quality, appropriate care every time they walk through the hospital, clinic, and medical office doors. AHRQ's research provides the basis for protocols that prevent medical errors and reduce hospital-acquired infections (HAI), and improve patient experiences and outcomes. In just one example, AHRQ's evidence-based Comprehensive Unit-based Safety Program to Prevent Healthcare-Associated Infections (CUSP)—first applied on a large scale in 2003 across more than 100 ICUs across Michigan—saved more than 1,500 lives and nearly \$200 million in the program's first 18 months. The protocols have since been expanded to hospitals in all 50 States, the District of Columbia, and Puerto Rico to continue the national implementation of this approach for reducing HAIs.

AHRQ helps health care providers—from private practice physicians to large hospital systems—understand how to deliver the best care most efficiently. For example, AHRQ maintains the National Quality Measurement Clearinghouse (NQMC) to provide health care providers, health plans, delivery systems, and others with an accessible resource for quality measures and a one-stop-shop for benchmarks on providing more safe, effective and timely care. The breadth of evidence available from AHRQ empowers health care providers to understand not just how they compare to their peers, but also how to improve their performance to be more competitive.

COSSA recognizes the tremendous challenges facing our Nation's economy and acknowledges the difficult decisions that must be made to restore our country's fiscal health. Nevertheless, we believe that strong support for public health research is an essential part of the solution to the Nation's economic restoration. Strengthening our commitment to public health, through robust funding of the NIH, CDC, and

AHRQ is a critical element of ensuring the health and well-being of the American people and our economy.

PREPARED STATEMENT OF THE CORPORATE FRIENDS OF THE CENTERS FOR DISEASE
CONTROL AND PREVENTION (CDC)

My name is David Ratcliffe, and I am the Co-Chairman of the Corporate Friends of the Centers for Disease Control and Prevention (CDC), alongside Co-Chairman, John Rice of General Electric. I am testifying in support of CDC's budget for fiscal year 2014 and requesting that the Chairman and his colleagues on the Senate Labor, Health and Human Services, Education and Related Agencies Subcommittee consider restoring CDC's budget authority to the fiscal year 2010 level of \$6.39 billion. I am also asking the Committee to consider allowing more flexibility for the Director of the CDC with his annual budget.

Chairman Harkin, Ranking Member Moran, and distinguished members of the subcommittee, it is my honor to submit a statement on behalf of the Corporate Friends of CDC. My message to Congress is that, while cuts to the Federal budget may be inevitable and indeed necessary, CDC should not be targeted for disproportionately large cuts. CDC is our Nation's designated health protection agency and an operating division of the Department of Health and Human Services. We must protect CDC's core mission of securing Americans from health threats, saving American lives, and saving money by keeping Americans healthy.

As a Federal agency, CDC cannot and does not advocate or lobby on its behalf. The Corporate Friends is a registered 501(c) 4 corporation structured to provide advocacy and education efforts about CDC's significance to our Nation's health and safety. As a former President and CEO of Southern Company, I fully support CDC's operation as vitally important to our Nation's security. Much like our Department of Defense protects Americans from military threats; CDC is committed to its job of protecting Americans from health, safety and security threats both foreign and domestic. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC and its collaboration with State and local health departments are our first line of defense. CDC applies groundbreaking health and medical research and real-time emergency response to keep America healthy, safe, and secure.

Since 2011, I have had the privilege of working closely with one of Atlanta's most treasured resources, the CDC. The CDC is unique in that it is one of the only Federal agencies headquartered outside of the Washington, D.C. beltway. This makes the connection to corporations and what CDC does even more evident. Atlanta is my hometown, along with 5 million other people, and CDC is a substantial contributor to employment, investment and tax base in Georgia, with almost \$940 million in payroll annually to Georgia, and over 8,000 employees, making it one of the State's top 15 employers.

I see firsthand that CDC's research science and outreach keeps employees and their families safe and healthy, while ensuring that our businesses can compete around the world in a safe, healthy environment. CDC is vital to a healthy national workforce and economy. CDC contributions expand well beyond Georgia, as more than 70 percent of CDC's funding goes to State and local agencies across the U.S. By doing so, CDC further sets the standard for action-oriented public health initiatives and research. CDC provides emergency preparedness and response 24/7 to any health threat. Through its efforts CDC has prevented 5–10 million cases of influenza, 30,000 hospitalizations, and about 1,500 deaths in the U.S. In the past few years, CDC has conducted more than 750 field investigations on health threats in the U.S. and in more than 35 countries. Whether through its global health initiatives or local foodborne illness investigations, the work of the CDC could not be more important. CDC's world-class work and importance to our Nation's economic health and security is not lost on the voting public who national polls, now, for many years have voted CDC as the most trusted agency of the Federal Government.

Therefore, I must express my concern for CDC's budget outlook for fiscal years 2013 and 2014. For Fiscal 2013, as a result of the sequestration and the President's recently announced plan to allocate funding within the Prevention and Public Health Fund, CDC's program authority will total \$6.291 billion, which represents a \$575 million or 8.4 percent reduction from Fiscal 2012 levels. For Fiscal 2014, the President's budget would reduce CDC's Budget Authority \$432 million below its fiscal year 2012 levels and \$228 million less than the Fiscal 2013 post-sequestration level. By comparison, the President's Fiscal 2014 Budget Authority level for CDC is more than \$1 billion less than CDC's Fiscal 2010 Budget Authority level.

Mr. Chairman, I respectfully request that you restore CDC's Budget Authority in your Fiscal 2014 Labor, Health and Human Services Appropriations bill to CDC's Fiscal 2010 level, as a commitment to our Nation's safety against current and unknown health threats. It is important for the Members of the Committee to understand that CDC's budget has been cut almost five percent, yet our Nation's health threats continue to grow.

The current and future budgetary challenges and economic landscape make the need for a strong CDC greater than ever. Recession-driven cuts in Federal, State, and local spending have reduced public health workers by about a fifth. The latest round of budget cuts and the fact that CDC's 2013 budget is locked into Fiscal 2012 budgetary priorities, as a result of Congress' inability to pass a Fiscal 2013 Labor, Health and Human Services Appropriations bill, provide even less flexibility for the CDC Director to improve the effectiveness of his budget and to respond to unanticipated and emerging public health threats. Americans and the American corporations, for whom I speak, want to know that they will be protected from a possible meningitis outbreak, E. coli threat, a whooping cough outbreak, chemical and biological terrorist threats, a new virus or other unknown epidemic. The snowballing impact of proposed cuts, from annual budgeting or sequestration, reduces the ability of the CDC to swiftly respond to problems.

Unless we can change proposed allocations and give the CDC director more flexibility to better use more limited resources, long standing core programs like Immunization Services across the country and Infectious Disease detection and response at CDC will be compromised. Prevention and public health are best buys, and in many cases can help reduce long-term health costs and save taxpayer dollars. The world, our country and our national and global workforces are facing more drug resistance and emerging diseases, and protection against this is being compromised. Disease knows no borders and affects people anywhere and everywhere. We need CDC to protect the health of the world, and also the health of the economy. The CDC is the Nation's defense department for health, working 24/7 to protect Americans from health safety and security threats that could negatively impact our bottom lines.

On behalf of the Corporate Friends of CDC, I am happy to be a resource to you all as you anticipate the 2014 budgeting process, so please do not hesitate to contact me.

PREPARED STATEMENT OF THE COUNCIL ON SOCIAL WORK EDUCATION

On behalf of the Council on Social Work Education (CSWE), I am pleased to offer this written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for inclusion in the official Committee record. I will focus my testimony on the importance of fostering a skilled, sustainable, and diverse social work workforce to meet the health care needs of the Nation through professional education, training, and financial support programs for social workers at the Department of Health and Human Services (HHS).

CSWE is a nonprofit national association representing more than 2,500 individual members and more than 700 master's and baccalaureate programs of professional social work education. Founded in 1952, this partnership of educational and professional institutions, social welfare agencies, and private citizens is the sole accrediting body for social work education in the United States. Social work education prepares students for leadership and professional interdisciplinary practice with individuals, families, groups, and communities in a wide array of service sectors, including health, mental health, adult and juvenile justice, PK-12 education, child welfare, aging, and others. Social work practice is facilitated by a collaborative relationship that empowers people to be healthy, productive, contributing members of their communities.

Recruitment and retention in social work continues to be a serious challenge that threatens the workforce's ability to meet societal needs. The U.S. Bureau of Labor Statistics estimates that employment for social workers is expected to grow faster than the average for all occupations through 2018, particularly for social workers specializing in the aging population and working in rural areas. In addition, the need for social workers specializing in mental health and substance use is expected to grow by almost 20 percent over the 2008-2018 decade.¹

CSWE understands the difficult funding decisions Congress is faced with this year given the challenging budget climate. In these challenging times, it is my hope that

¹ U.S. Bureau of Labor Statistics. 2009. *Occupational Outlook Handbook, 2010-11 Edition: Social Workers*, <http://data.bls.gov/cgi-bin/print.pl/oco/ocos060.htm>. Retrieved March 28, 2012.

the Committee will prioritize funding for health professions training in fiscal year 2014 to help to ensure that the Nation continues to foster a sustainable, skilled, and culturally competent workforce that will be able to keep up with the increasing demand for social work services and meet the unique health care needs of diverse communities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

TITLE VII AND TITLE VIII HEALTH PROFESSIONS PROGRAMS

CSWE urges the Committee to provide \$520 million in fiscal year 2014 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through HRSA, which is equal to the fiscal year 2012 enacted level. HRSA's Title VII and Title VIII health professions programs represent the only Federal programs designed to train health care providers in an interdisciplinary way to meet the health care needs of all Americans, including the underserved and those with special needs. These programs also serve to increase minority representation in the health care workforce through targeted programs that improve the quality, diversity, and geographic distribution of the health professions workforce. The Title VII and Title VIII programs provide loans, loan guarantees and scholarships to students, and grants to institutions of higher education and non-profit organizations to help build and maintain a robust health care workforce. Social workers and social work students are eligible for funding from the suite of Title VII health professions programs.

The Title VII and Title VIII programs were reauthorized in 2010, which helped to improve the efficiency of the programs as well as enhance efforts to recruit and retain health professionals in underserved communities. Recognizing the severe shortages of mental and behavioral health providers within the health care workforce, a new Title VII program was authorized in the Patient Protection and Affordable Care Act (Public Law 111-148). The Mental and Behavioral Health Education and Training Grants program provides grants to institutions of higher education (schools of social work and other mental health professions) for faculty and student recruitment and professional education and training. The program received first-time funding of \$10 million in the final fiscal year 2012 appropriations bill. The President's fiscal year 2014 budget request would expand the program through a partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA) to expand the mental health workforce by almost 3,500 professionals focused on transition-age youth (16-25). CSWE urges the Committee to maintain funding for this critically important program at the highest level possible in fiscal year 2014. CSWE supports the proposed expansion of the program but encourages the committee to be inclusive of non-youth populations needing mental and behavioral health services and not to reduce the scope of the original intent of the program through the expansion. This is the only program in the Federal Government that is explicitly focused on recruitment and retention of social workers and other mental and behavioral health professionals.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION (SAMHSA)

MINORITY FELLOWSHIP PROGRAM

CSWE urges the Committee to appropriate the highest level possible for the Minority Fellowship Program (MFP) in fiscal year 2014. The goal of the SAMHSA Minority Fellowship Program (MFP) is to achieve greater numbers of minority doctoral students preparing for leadership roles in the mental health and substance use fields. According to SAMHSA, minorities make up approximately one-fourth of the population, but only 10 percent of mental health providers come from ethnic minority communities. CSWE is one of six grantees of this critical program and administers funds to exceptional minority doctoral social work students. Other grantees include national organizations representing nursing, psychology, psychiatry, marriage and family therapy, and professional counselors. SAMHSA makes grants to these six organizations, who in turn recruit minority doctoral students into the program from the six distinct professions. CSWE administers the funds to qualified doctoral students and helps facilitate mentoring and networking throughout the duration of the fellowship as well as facilitates an alumni group to help continue to engage former fellows long after their formal fellowship has ended.

Since its inception in 1974, the MFP has helped support doctoral-level professional education for over 1,000 ethnic minority social workers, psychiatrists, psychologists, psychiatric nurses, and family and marriage therapists. Still, the program continues to struggle to keep up with the demands that are plaguing these health professions. Severe shortages of mental health professionals often arise in

underserved areas due to the difficulty of recruitment and retention in the public sector. Nowhere are these shortages more prevalent than within Tribal communities, where mental illness and substance use go largely untreated and incidences of suicide continue to increase. Studies have shown that ethnic minority mental health professionals practice in underserved areas at a higher rate than non-minorities. Furthermore, a direct positive relationship exists between the numbers of ethnic minority mental health professionals and the utilization of needed services by ethnic minorities.² The President's fiscal year 2014 budget request includes \$9.4 million for MFP core activities; CSWE urges the committee to support this request.

Thank you for the opportunity to express these views. Please do not hesitate to call on the Council on Social Work Education should you have any questions or require additional information.

PREPARED STATEMENT OF THE CROHN'S AND COLITIS FOUNDATION OF AMERICA
SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) \$32 billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2013. Increase funding for the National Cancer Institute (NCI), The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
 - 2) Continued focus on Digestive Disease Research and Education at NIH, including Inflammatory Bowel Disease (IBD) and Colorectal Cancer.
 - 3) \$6,860,000 for the Centers for Disease Control and Prevention's (CD C) IBD Epidemiology Activities.
 - 4) \$50 million for the Center for Disease Control and Prevention's (CDC) Colorectal Cancerscreening and Prevention Program.
-

Thank you for the opportunity to again submit testimony to the subcommittee. CCFA has remained committed to its mission of finding a cure for Crohn's disease and ulcerative colitis and improving the quality of life of children and adults affected by these diseases for over 46 years. Impacting an estimated 1.4 million Americans, 30 percent of whom are diagnosed in their childhood years, Inflammatory Bowel Diseases (IBD) are chronic disorders of the gastrointestinal tract which cause abdominal pain, fever, and intestinal bleeding. IBD represents a major cause of morbidity from digestive illness and has a devastating impact on both patients and their families.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The CCFA would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the CCFA recommends:

- \$32 billion for the NIH.
- \$2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the CCFA respectfully request that any increase for NIH does not come at the expense of

other Public Health Service agencies. With the competing and the challenging budgetary constraints the subcommittee currently operates under, the CCFA would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as IBD. These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever.

²U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/cre/sma-01-3613.pdf>.

Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The CCFA encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The CCFA urges the Consortium to continue its work in IBD research.

CENTERS FOR DISEASE CONTROL AND PREVENTION IBD EPIDEMIOLOGY

CDC, in collaboration with a nationwide, geographically diverse network of large managed health care delivery systems, has led an epidemiological study of IBD to understand IBD incidence, prevalence, demographics, and healthcare utilization. The group, comprised of investigators at the Massachusetts General Hospital in Boston, Rhode Island Hospital, the Crohn's and Colitis Foundation of America, and CDC, has piloted the Ocean State Crohn's and Colitis Registry (OSCAR), which includes both pediatric and adult patients. Since 2008, the OSCAR investigators have recruited 22 private-practice groups and hospital based physicians in Rhode Island and are that enrolling newly diagnosed patients into the registry. This study found an average annual incidence rate of 8.4 per 100,000 people for Crohn's disease and 12.4 per 100,000 for Ulcerative Colitis; published in *Inflammatory Bowel Disease Journal*, April 2007.

—Over the course of the initial 3-year epidemiologic collaboration, CDC laboratory scientists and epidemiologists worked to improve detection tools and epidemiologic methods to study the role of infections (infectious disease epidemiology) in pediatric IBD, collaborating with extramural researchers who were funded by a National Institutes of Health (NIH) research award.

—Since 2006, CDC epidemiologists have been working in conjunction with the Crohn's and Colitis Foundation of America and a large health maintenance organization to better understand the natural history of IBD and factors that predict the course of disease.

The Crohn's and Colitis Foundation of America encourages the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2014.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The CCFA recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

CONCLUSION

The CCFA understands the challenging budgetary constraints and times we live in that this subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of our patients, we appreciate your consideration of our view. We look forward to working with you and your staff.

PREPARED STATEMENT OF THE CURE CMD

On behalf of the thousands of Americans with Congenital Muscular Dystrophy (CMD), we urge the subcommittee to support the National Institutes of Health (NIH) at \$32 billion in fiscal year 2014.

Cure CMD is a nonprofit organization dedicated to finding treatments and, eventually, a cure for the devastating ravages of the congenital muscular diseases. CMD is a group of diseases causing muscle weakness at birth or within the first 2 years

of childhood. Several defined genetic mutations cause muscles to break down faster than they can repair or grow. A child with CMD may have various neurological or physical impairments and may never gain the ability to walk. Cure CMD represents the network of family, friends, caretakers and affected individuals tirelessly battling this devastating disease every day. Aubrey, Katie, and Maia are just a few of the affected population, but their stories are common among the CMD community. An introduction to their stories is below:

Aubrey has never been able to stand, sit up unaided, or even roll over. Despite her challenges, she remains an energetic, intelligent and enthusiastic 6½-year-old. The most challenging part of her overall weakness is her inability to cough—leaving her susceptible to frequent respiratory illness. A simple runny nose can very quickly turn into pneumonia. In her short life, she, like many children with CMD, has been hospitalized with pneumonia multiple times. With each admission, parents often wonder whether their child will be strong enough to fight through it again. It is a long and difficult battle.

Katie, an honors student in college, lost her ability to walk in sixth grade. Weighing just 55 pounds, Katie needs help showering, getting dressed, brushing her hair, preparing a meal, getting books from her backpack and breathing with a machine at night. On a college study abroad trip to France earlier this year, Katie suffered acute respiratory failure. She required specialized care and fully recovered because Cure CMD guided the entire care process from the U.S. with physicians in France.

Maia, 15-year-old with CMD, is a profoundly disabled teen who overcame tremendous odds through her sheer determination and resolve of her family, therapists and school aides. She has the great misfortune of receiving multiple disadvantages: static cognitive impairment and progressive muscle weakness. Her speech is limited to 5 words.

CMD is a progressive disease without treatment. The future is bleak. It is a life that ends after years of non-stop caregiving, dependency, hospitalizations and loss . . . loss of ambulation, loss of integration within society, loss of ability to sign and communicate, loss of an ability to breathe on one's own and loss of life.

Cure CMD is deeply appreciative of the critical support NIH has provided to congenital muscular dystrophy research and the organization's steadfast pathway toward clinical trials. With help from the NIH, in just 5 years Cure CMD has brought scientists together from around the world to work toward common therapeutic targets, launched an International Patient Registry, created a CMD family conference to share learnings, developed a bio bank for investigators and created new care guidelines for families and physicians—the first step in “treatment” to improve and save the lives of people with CMD.

The research NIH supports is making significant advances in better understanding and treating CMD. Without this vital research, the CMD community will be setback years in making progress and improving the quality of life of those suffering with this devastating disorder.

We respectfully ask the subcommittee to encourage NIH to continue to support grants and other funding mechanisms to advance key congenital muscle disease initiatives for clinical trial readiness. Furthermore, we would like the subcommittee to request an update from NIH in future fiscal year congressional budget justifications on total dollars spent on congenital muscular dystrophy and congenital myopathy research.

We applaud the subcommittee's past support of NIH and urge you to fund NIH at \$32 billion in fiscal year 2014. We understand the need for fiscal responsibility, but this cannot come at the expense of research that could significantly impact the daily lives of those living with CMD.

PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

On behalf of the Cystic Fibrosis Foundation and the 30,000 people with cystic fibrosis (CF) in the United States, we submit the following testimony to the Senate Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education, and Related Agencies on our funding requests for fiscal year 2014.

The Cystic Fibrosis Foundation remains significantly concerned about the impact of the recently-enacted sequester and other funding reductions on biomedical research and the health of the CF population. The Foundation requests the highest possible funding level for the National Institutes of Health, its National Center for Advancing Translational Sciences, and programs that provide access to health care in fiscal year 2014, in order to support continued scientific discoveries and promote the well-being of those living with this serious illness.

Developing Cystic Fibrosis Treatments and a Cure through NIH Funding

As the Committee considers its funding priorities for the coming fiscal year, we urge consideration of the critical role that NIH plays in the development of treatments for cystic fibrosis and other diseases and respectfully request increased funding for this vital agency.

NIH-funded advances like the mapping of the human genome and the development of high throughput screening were essential to the creation of Kalydeco™, a cystic fibrosis treatment approved in January 2012 and called “the most important drug of 2012” by Forbes Magazine. This breakthrough drug, developed by Vertex Pharmaceuticals in cooperation with the Cystic Fibrosis Foundation, is the first to treat the underlying cause of cystic fibrosis in those with a particular genetic mutation of CF that impacts about 4 percent of the CF population. More exciting advancements are in the pipeline, as phase 3 clinical trials are underway to study a combination of Kalydeco and a new compound, VX-809. This combination would treat those with the most common CF mutation, comprising about 50 percent of those with CF in the United States.

Other NIH-funded research could be the key to future cystic fibrosis treatments, such as research conducted through NIH’s pediatric liver disease consortium at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), which helps researchers discover treatments for CF-related liver disease and other diseases that affect thousands of children each year.

NIH also issued two Requests for Applications (RFAs) last year that specifically target cystic fibrosis, one to study early lung disease and the other to study cystic fibrosis-related diabetes, both of which could lead to new scientific discoveries. The agency also invests in research at the University of Iowa that studies the effects of CF in both pig and ferret models. The ferret model in particular is expected to be uniquely informative of early events in CF-related diabetes and will complement the ongoing work done through the NIDDK’s RFA efforts.

CF-related genetic research also benefits from Federal funding. Research into cystic fibrosis transmembrane conductance regulator (CFTR) folding and trafficking and CFTR protein structure is critical to the creation of new drugs that treat the underlying cause of the disease. The data that emerged from Kalydeco Phase 2 and 3 clinical trials provided proof that CFTR protein function modulation, the mechanism by which this drug targets the physiological defect in those with a particular CF mutation, is a viable therapeutic approach. More NIH-funded research is needed to understand the more than 1,000 other genetic mutations of CF.

Lastly, it is important to note that NIH funding benefits the economy, supporting more than 402,000 jobs and \$57 billion in economic output in 2012 according to a report by United for Medical Research. Funding for NIH also attracts the next generation of promising researchers through programs like the National Research Service Awards (NRSA). Robust funding for NIH promotes much-needed economic growth and supports the scientific progress that makes the United States the worldwide leader in biomedical research.

Advancing Innovation Through Translational Science

The Cystic Fibrosis Foundation strongly supports efforts to strengthen the field of translational science and urges the Committee to increase funding for the NIH’s National Center for Advancing Translational Sciences (NCATS). NCATS’ use of innovative methods and technologies to improve the development, testing and implementation of diagnostics and therapeutics improves the efficiency of the translation of basic scientific discoveries into new therapies and advances the search for cures.

Certain NCATS programs are integral to the center’s success and merit special consideration. These include the Clinical and Translational Science Awards (CTSA), the Cures Acceleration Network (CAN) and the Therapeutics for Rare and Neglected Diseases (TRND) program, all designed to support clinical and translational research and transform the way in which it is conducted and funded. TRND in particular, inspired by the Cystic Fibrosis Foundation’s Therapeutics Development Network of clinical research centers, is essential to the advancement of treatments for rare illnesses.

NCATS also emphasizes collaboration across sectors, promoting more efficient and innovative drug discovery and development. For example, the center is working with the Defense Advanced Research Projects Agency (DARPA) and the Food and Drug Administration (FDA) to design a tissue chip for drug screening. This chip, composed of diverse human cells and tissues, mimics how drugs interact with the human body. If successful, this chip could make drug safety and efficacy assessments possible at an earlier stage in drug development, enabling investigators to concentrate on the most promising new drugs.

Other significant collaborative projects include the Regulatory Science Initiative and the FDA–NIH Joint Leadership Council. As treatments like Kalydeco are developed to target specific genetic mutations and smaller populations, collaborative efforts between NIH, FDA and others in Government, industry and academia will promote the swift advancement of therapies from the laboratory to the patients who need them most.

Promoting Access to Quality, Specialized Health Care

The Cystic Fibrosis Foundation encourages robust funding for provisions of the Affordable Care Act (ACA) that ensure affordable access to quality, specialized health care for those with cystic fibrosis.

In order to receive the highest quality care, people with CF require treatment by a multidisciplinary team of providers who specialize in CF and practice at an accredited CF care center. Cystic fibrosis patients also need a variety of drugs and therapies to keep them healthy, many requiring 2–3 hours of treatment per day.

Cystic fibrosis is also an expensive disease. People with cystic fibrosis typically have medical costs 15 times greater than an average person. Unfortunately, the high cost of CF care is increasingly passed on to patients, placing a financial burden on those already struggling with a serious, chronic illness. Twenty 5 percent of CF patients in a recent survey reported that they have delayed or skipped medical care due to cost, and 31 percent said they skipped doses of medication or took less than prescribed due to cost concerns.

Affordable insurance that provides coverage for comprehensive, specialized care and medications allows those with CF to access the best treatment available for this difficult disease. High co-payments, excessive co-insurance rates and unnecessary prior authorization requirements are burdensome barriers for those who need treatment to stay healthy.

We urge the Committee to provide sufficient funding for the ACA provisions that will help those with cystic fibrosis afford the care they need, including the expansion of the Medicaid program, the development of Health Insurance Marketplaces to ensure adequate and affordable coverage for high-quality, specialized cystic fibrosis care and the creation of Essential Health Benefits that include access to specialized CF care centers and medications and prevent overly burdensome barriers to needed treatments.

About Cystic Fibrosis and the Cystic Fibrosis Foundation

Cystic fibrosis is a rare genetic disease that causes the body to produce abnormally thick mucus that clogs the lungs and results in life-threatening infections. This mucus also obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food.

The Cystic Fibrosis Foundation's mission is to find a cure for CF and improve the quality of life for those living with the disease. Through the Foundation's efforts, the life expectancy of a child with CF has doubled in the last 30 years and research to find a cure is more promising than ever. The Foundation's research efforts have helped create a robust pipeline of potential therapies that target the disease from every angle. Nearly every CF drug available today was made possible because of the Foundation's support and our ongoing work to find a cure.

Once again, we urge the Committee to increase funding for biomedical research at the National Institutes of Health and for programs that provide access to specialized health care in fiscal year 2014. We stand ready to work with the Committee and Congressional leaders on the challenges ahead. Thank you for your consideration.

PREPARED STATEMENT OF THE DEANS' NURSING POLICY COALITION

Dear Chairman Harkin and Ranking Member Moran: As the subcommittee begins its deliberations on the fiscal year 2014 Labor, HHS, and Education appropriations bill, we write as members of the Deans' Nursing Policy Coalition (the Coalition) to urge you to protect and sustain funding for nursing science, research, practice, and education programs, which are critical to our efforts to provide high-quality, affordable care for a growing and increasingly diverse patient population.

The Coalition comprises seven top research-based schools of nursing that generate evidence for effective health care practice and translate that knowledge to the education and policy environments. As leaders in graduate-level nursing, our schools also focus on educating advanced practice nurses to direct patient care in clinical settings, expert faculty practitioners to train the next generation of nurses, and Ph.D.-level nurse researchers to conduct cutting-edge research that promotes health

and helps manage chronic conditions such as diabetes, obesity and cardiovascular disease.

The Coalition's funding priorities play a foundational role in supporting the nursing profession. We urge you to support the following agencies and programs:

- National Institutes of Health (NIH), including \$150 million for the National Institute for Nursing Research (NINR), which funds research that establishes the scientific basis for disease prevention, cancer care, health promotion, and high quality nursing care;
- At least \$231 million for the Nursing Workforce Development Programs at the Health Resources and Services Administration (HRSA) to build a more highly educated nursing workforce, as recommended by the Institute of Medicine's report, *The Future of Nursing: Leading Change, Advancing Health*; and
- As much funding as possible for Nurse-Managed Health Clinics (NMHCs), funded through Title III of the Public Health Service Act, which will enable nurses to help expand and improve delivery of care.

National Institutes of Health; National Institute of Nursing Research

As our top priority, we urge you to support a funding request of at least \$32 billion for NIH in fiscal year 2014. Of particular importance to the Coalition is NINR, the smallest institute at NIH and an important source of Federal funding for nursing science and research. We respectfully request \$150 million for NINR in fiscal year 2014.

Nursing science is the care of people. Through NINR awards, nurse researchers investigate strategies to prevent chronic health conditions, such as diabetes, heart disease and HIV/AIDS; provide symptom management for cancer patients; promote health and healthier treatment outcomes; eliminate health disparities by identifying culturally appropriate interventions and care strategies; and improve processes and strategies for palliative care, easing suffering at the end of life. NINR supports research that is highly translational, focused on the effectiveness and cost-effectiveness of health care interventions.

In fact, much of the care patients receive in hospital settings today is based on NINR research and is widely adopted as best practices by physicians, hospitals and insurers. For example, chronic diseases cause seven out of every 10 deaths in the United States and are among the most costly and preventable health problems. NIH support to Emory University is helping nurse researchers address this growing epidemic by launching an inter-professional education and mentoring program to prepare nurse scientists for the challenges of translating scientific research for chronically ill patients.

Nursing Workforce Development Programs

We also urge you to provide at least \$231 million for HRSA's Nursing Workforce Development programs (Title VIII of the Public Health Service Act), the largest source of dedicated funding for nurse education. Of specific interest to the Coalition, Title VIII programs support future nurse faculty, such as the Advanced Education Nurse Program and the Nurse Faculty Loan Program. According to the American Association of Colleges of Nursing's most recent survey, the nursing shortage is caused and perpetuated by insufficient numbers of nurse faculty and clinical preceptors, not a lack of interested and academically qualified students.

The Coalition appreciates the budgetary challenges associated with the current fiscal environment, but we believe that these programs are critical to promote academic progression, as highlighted in the IOM report, and to enable nursing schools to open admissions, expand student capacity, and ensure a supply of qualified nurse professionals.

Nurse-Managed Health Clinics

Finally, we urge you to designate as much as possible for Nurse-Managed Health Clinics (Title III of the Public Health Service Act, administered by HRSA) in fiscal year 2014 and to reject the Administration's actions to merge NMHCs with federally Qualified Health Clinics (FQHCs).

NMHCs, closely linked to schools of nursing, were created under the Affordable Care Act as part of a comprehensive primary care workforce development strategy; the program was authorized at \$50 million. Although a small amount of funding from other sources was made available for NMHCs in fiscal years 2010 through 2012, this important and cost-effective program has been hindered by inconsistent funding and administration. We remain concerned that the President has folded NMHCs into the Community Health Center program; the Administration's approach contains an explicit expectation for current and new NMHCs to become FQHCs, sacrificing the unique qualities of NMHCs in the process. FQHCs operate under a number of very rigid requirements related to governance and administration which are

not likely to be modified. Coming into compliance with those requirements will cause NMHCs to lose many of the attributes that make them excellent sites for nurse education and for development of improved care models.

Of particular importance to the Coalition, each NMHC is required under the ACA to be affiliated with a school, college, university or department of nursing, or independent nonprofit health or social services agency, and plays an important role in nurse education, serving as clinical education and practice sites for students and faculty. FQHCs are not required to partner with schools of nursing and as the NMHC program is merged with FQHCs and required to meet new governance requirements, schools of nursing will lose an important teaching site for their student nurses and for other health professionals on interdisciplinary teams.

We understand that the subcommittee and the Congress will need to make difficult decisions regarding fiscal year 2014 and the larger budget environment, but we urge you to consider the impact of recent funding reductions—and the threat of additional cuts—to programs designed to educate and train our health care workforce to meet the needs of the American public. We greatly appreciate your leadership on nursing issues and consideration of these requests.

Sincerely,

Bobbie Berkowitz, PhD, RN, FAAN, Dean and Professor, Columbia School of Nursing, Senior Vice President, Columbia University Medical Center; Colleen Conway-Welch, PhD, CNM, FAAN, FACNM, Nancy & Hilliard Travis Professor of Nursing, Dean, Vanderbilt University School of Nursing; Catherine L. Gilliss, PhD, RN, FAAN, Dean and Helene Fuld Health Trust Professor of Nursing, Duke University School of Nursing, Vice Chancellor for Nursing Affairs, Duke University; Margaret Grey, DrPH, RN, FAAN, Dean and Annie Goodrich Professor, Yale University School of Nursing; Linda A. McCauley, RN, PhD, FAAN, Dean and Professor, Nell Hodgson Woodruff School of Nursing, Emory University; Afaf I. Meleis, PhD, DrPS(hon), FAAN, Margaret Bond Simon Dean of Nursing, University of Pennsylvania School of Nursing; Kathy Rideout, EdD, PNP-BC, FNAP, Dean, University of Rochester School of Nursing.

PREPARED STATEMENT OF THE DIABETES ADVOCACY ALLIANCE™ (DAA)

Dear Chairman Harkin and members of the subcommittee: The Diabetes Advocacy Alliance™ (DAA), a coalition of 19 members representing patient advocacy organizations, professional societies, trade associations, other nonprofit organizations, and corporations committed to changing the way diabetes is viewed and treated in America, is pleased to provide this written testimony in support of funding for the National Diabetes Prevention Program (National DPP). As you craft the fiscal year 2014 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, the DAA urges you to include \$20 million in funding for the National DPP.

Since the National DPP was first established in the Affordable Care Act (ACA) with the goal to “eliminate the preventable burden of diabetes,” the DAA has advocated strongly for Federal funding to bring the program to scale nationally. A unique public-private partnership that seeks to roll out across the country clinically-proven, community-based diabetes prevention programs targeted to people with prediabetes, the National DPP received \$10 million in Federal funding in 2012 and the Senate appropriated \$20 million in fiscal year 2013 that was never enacted. The National DPP has received no Congressional funding since 2012—despite the continuing growth in diabetes prevalence across the Nation.

The Diabetes Epidemic and its Toll Continues Unabated

Currently 26 million Americans have diabetes, and another 79 million have prediabetes and are at high risk for developing type 2 diabetes within seven to 10 years.¹ In fact, 70 percent of those with prediabetes could progress to type 2 diabetes without intervention.² Over the past 30 years, the percentage of Americans diagnosed with diabetes has more than doubled.³ According to the Centers for Disease Control and Prevention (CDC), as many as 1 in 3 adults could have diabetes by the

¹ CDC National Diabetes Factsheet 2011. Available at CDC website: <http://www.cdc.gov/diabetes/pubs/factsheet11.htm>. Accessed April 15, 2013.

² Geiss LS, James C, Gregg EW et al. Diabetes Risk Reduction Behaviors among US Adults with Prediabetes. *American Journal of Preventive Medicine*. 2010. 38(4):403–409.

³ CDC National Diabetes Factsheet 2011. Available at CDC website: <http://www.cdc.gov/diabetes/pubs/factsheet11.htm>. Accessed April 15, 2013.

year 2050.⁴ Even among the youth of our nation—who historically have not developed type 2 diabetes—rates of the disease are on the rise. In fact, a CDC study projects that the number of children with type 2 diabetes will increase by nearly 50 percent by 2050 if current trends continue. If type 2 diabetes incidence increases even slightly, mirroring other countries, the rate of type 2 diabetes among children in the U.S. could grow fourfold by 2050.⁵

Diabetes is a gateway disease, often leading to life-altering complications. The longer people live with diabetes, the more likely it is that they will develop complications that include heart attack, stroke, blindness, kidney failure and limb amputations.⁶ Each day, because of diabetes, 230 people have limbs amputated, 120 people develop kidney failure, and 55 people go blind.⁷ Diabetes and its complications shorten the life expectancy of those living with the disease by seven to 8 years.⁸

Diabetes affects our Nation's fiscal health as well. In 2012, the Nation spent \$245 billion on diagnosed diabetes, an increase of 41 percent from 2007.⁹

Type 2 Diabetes: A Chronic Disease we Know How to Prevent

Despite these grim statistics, there is hope for bending the impact curve of diabetes and altering both the human and economic toll of the disease—and that hope is the National DPP. The National DPP is based on a clinically-proven program, the National Institutes of Health-funded Diabetes Prevention Program, which showed that adults with prediabetes could reduce their risk for developing type 2 diabetes by up to 58 percent through moderate weight loss and regular physical activity. Older adults, those age 60 and over, who made these same lifestyle changes reduced their risk of developing type 2 diabetes by 71 percent.¹⁰ Follow-up research confirmed that these positive outcomes persist for at least a decade after participating in the lifestyle intervention and that the program can be offered effectively and cost-effectively within group settings at YMCAs and other community-based locations.¹¹

More recent research, published just this month, examined the 10-year effectiveness of the DPP among participants who were adherent to the lifestyle intervention—those who lost at least 5 percent of their body weight—and showed that the lifestyle intervention, which is essentially the National DPP, “represents a good value for money.” And it improved the quality of life for participants.¹²

The Promise of the National DPP: A Public-Private Partnership that is Getting Results

The National DPP, administered through the CDC, can help improve our Nation's health by halting or stopping the progression to type 2 diabetes; and improve our fiscal health as well by decreasing what we spend on treating diabetes and its life-altering complications. If fully scaled, the NDPP holds the promise of delivering cost-effective diabetes prevention programs in communities across the Nation to the 79 million Americans at high risk for diabetes.

The National DPP authorized in the Affordable Care Act, got its start as a public-private partnership in 2010 when the YMCA of the USA (Y-USA) partnered with the CDC's National Diabetes Prevention Program and the Diabetes Prevention and Control Alliance to offer diabetes prevention programs cost effectively at local Ys.

⁴Boyle JP, Thompson TJ, Gregg EW, Barker LE, Williamson DF. Projection of the Year 2050 Burden of Diabetes in the US Adult Population: Dynamic Modeling of Incidence, Mortality and Prediabetes Prevalence. *Population Health Metrics*. 8(29), October 2010.

⁵Imperatore G et al. Projections of Type 1 and Type 2 Diabetes in the US Population Aged < 20 Years Through 2050. *Diabetes Care*. 35(12), December 2012.

⁶CDC National Diabetes Factsheet 2011. Available at CDC website: <http://www.cdc.gov/diabetes/pubs/factsheet11.htm>. Accessed April 15, 2013.

⁷American Diabetes Association. Diabetes: A National Epidemic, January 2008. Available at: <http://house.gov/degette/diabetes/docs/Diabetes%20A%20National%20Epidemic.fs.08.pdf>. Accessed April 15, 2013.

⁸Franco OH, Steyerberg EW, Hu FB et al. Associations of Diabetes Mellitus with Total Life Expectancy and Life Expectancy with and without Cardiovascular Disease. *Archives of Internal Medicine*. 2007;167:1145–51.

⁹American Diabetes Association. Economic Costs of Diabetes in the US in 2012. Published online before print. *Diabetes Care*. March 6, 2013.

¹⁰Diabetes Prevention Program Research Group. Reduction in the Incidence of Type 2 Diabetes with Lifestyle Intervention or Metformin. *New England Journal of Medicine*. 346(6): 393–403, 2002.

¹¹Diabetes Prevention Program Research Group. 10-Year Follow Up of Diabetes Incidence and Weight Loss in the DPP0S. *Lancet*. 2009;374(9702): 1677–1686 and Ackermann RT, Finch EA, Brizendine e, Zhou H, Marrero DG. Translating the DPP into the Community: The DEPLOY Pilot Study. *American Journal of Preventive Medicine*. 2008;35(4): 357–63.

¹²Herman WH et al. Effectiveness and Cost Effectiveness of Diabetes Prevention among Adherent Participants. *American Journal of Managed Care*. 2013;19(3):194–202.

About 80 percent of U.S. households live within five miles of a Y. Through the partnership, four UnitedHealthcare plans were the first private plans to offer the program as a covered benefit and reimburse Ys on a pay-for-performance basis, including meeting weight loss goals. Since then, 18 additional plans from UnitedHealthcare, as well as Medica, MVP and Florida Blue have joined DPCA's network of payers. Today, Y-USA, the Diabetes Prevention and Control Alliance and many others are working with CDC in this successful public-private partnership to continue to roll out this program nationwide.

In fact, through the National DPP, the YMCA's Diabetes Prevention Program is now available at about 500 sites across 32 States. Approximately 9,000 individuals have enrolled and attended classes since 2010, and more than half of the participants have completed the full year-long program.

The Center for Medicare & Medicaid Innovation (CMMI) awarded a \$12 million Health Care Innovation Award to Y-USA, recognizing the YMCA'S Diabetes Prevention Program's success and cost-effectiveness. Under the grant, Y-USA will deliver its Diabetes Prevention Program to 10,000 adults age 65+ with prediabetes in 17 communities across the Nation, with an estimated cost savings to Medicare of \$4.2 million over 3 years and \$53 million over 6 years.

What \$20 Million in Federal Funding Will Provide

Providing \$20 million in Federal funding for the National DPP in fiscal year 2014 is a good investment for the Nation. It will:

- Put the program on track to reach 250,000 people with prediabetes;
- Establish five business outreach coalitions to engage and educate employers and insurers on the return on investment for offering proven lifestyle interventions for type 2 diabetes to high risk individuals.
- Support the provision of training nationally for individuals who will deliver the lifestyle intervention in community and clinical settings and worksites, and to develop a web-based learning center.
- Maintain the CDC's Recognition Program for the NDPP, which provides an imprimatur ensuring the quality, consistency, and integrity of the lifestyle intervention.
- Support a national awareness campaign to expand the adoption and impact of the National DPP.

According to the Urban Institute, rolling out evidence-based diabetes prevention programs nationally through the National DPP could save the Nation \$191 billion over the next decade—with 75 percent of savings going to Medicare and Medicaid.¹³

The National DPP is without question a good investment for the 79 million Americans with prediabetes and for our country. In closing, the DAA urges you to include \$20 million in funding for the National DPP in the fiscal year 2014 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill to bring this program to scale nationally for the 79 million Americans with prediabetes in the U.S. who are on a relentless march toward diabetes without intervention.

PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) \$32 billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2012. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
- 2) Continue focus on Digestive Disease Research and Education at NIH, including Inflammatory Bowel Disease (IBD), Hepatitis and Other Liver Diseases, Irritable Bowel Syndrome (IBS), Colorectal Cancer, Endoscopic Research, Pancreatic Cancer, and Celiac Disease.
- 3) \$50 million for the Centers for Disease Control and Prevention's (CDC) Hepatitis Prevention and Control Activities.
- 4) \$50 million for the Center for Disease Control and Prevention's (CDC) Colorectal Cancerscreening and Prevention Program.

Chairman Harkin, thank you for the opportunity to again submit testimony to the subcommittee. Founded in 1978, the Digestive Disease National Coalition (DDNC)

¹³Berenson RA et al. Urban Institute. How Can We Pay for Health Care Reform? July 2009.

is a voluntary health organization comprised of 33 professional societies and patient organizations concerned with the many diseases of the digestive tract. The DDNC promotes a strong Federal investment in digestive disease research, patient care, disease prevention, and public awareness. The DDNC is a broad coalition of groups representing disorders such as Inflammatory Bowel Disease (IBD), Hepatitis and other liver diseases, Irritable Bowel Syndrome (IBS), Pancreatic Cancer, Ulcers, Pediatric and Adult Gastroesophageal Reflux Disease, Colorectal Cancer, and Celiac Disease.

The social and economic impact of digestive disease is enormous and difficult to grasp. Digestive disorders afflict approximately 65 million Americans. This results in 50 million visits to physicians, over 10 million hospitalizations, collectively 230 million days of restricted activity. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year.

The DDNC would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

Specifically the DDNC recommends:

—\$2 billion for the NIH.

—\$2.16 billion for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK).

We at the DDNC respectfully request that any increase for NIH does not come at the expense of other Public Health Service agencies. With the competing and the challenging budgetary constraints the subcommittee currently operates under, the DDNC would like to highlight the research being accomplished by NIDDK which warrants the increase for NIH.

INFLAMMATORY BOWEL DISEASE

In the United States today about one million people suffer from Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain, and fever. Complications arising from IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. The cause of IBD is still unknown, but research has led to great breakthroughs in therapy.

In recent years researchers have made significant progress in the fight against IBD. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute. The DDNC would like to applaud the NIDDK for its strong commitment to IBD research through the Inflammatory Bowel Disease Genetics Research Consortium. The DDNC urges the Consortium to continue its work in IBD research. Therefore the DDNC and its member organization the Crohn's and Colitis Foundation of America encourage the CDC to continue to support a nationwide IBD surveillance and epidemiological program in fiscal year 2014.

VIRAL HEPATITIS: A LOOMING THREAT TO HEALTH

The DDNC applauds all the work NIH and CDC have accomplished over the past year in the areas of hepatitis and liver disease. The DDNC urges that funding be focused on expanding the capability of State health departments, particularly to enhance resources available to the hepatitis State coordinators. The DDNC also urges that CDC increase the number of cooperative agreements with coalition partners to develop and distribute health education, communication, and training materials about prevention, diagnosis and medical management for viral hepatitis.

The DDNC supports \$50 million for the CDC's Hepatitis Prevention and Control activities. The hepatitis division at CDC supports the hepatitis C prevention strategy and other cooperative nationwide activities aimed at prevention and awareness of hepatitis A, B, and C. The DDNC also urges the CDC's leadership and support for the National Viral Hepatitis Roundtable to establish a comprehensive approach among all stakeholders for viral hepatitis prevention, education, strategic coordination, and advocacy.

COLORECTAL CANCER PREVENTION

Colorectal cancer is the third most commonly diagnosed cancer for both men and woman in the United States and the second leading cause of cancer-related deaths. Colorectal cancer affects men and women equally.

The DDNC recommends a funding level of \$50 million for the CDC's Colorectal Cancer Screening and Prevention Program. This important program supports enhanced colorectal screening and public awareness activities throughout the United

States. The DDNC also supports the continued development of the CDC-supported National Colorectal Cancer Roundtable, which provides a forum among organizations concerned with colorectal cancer to develop and implement consistent prevention, screening, and awareness strategies.

PANCREATIC CANCER

In 2013, an estimated 33,730 people in the United States will be found to have pancreatic cancer and approximately 32,300 died from the disease. Pancreatic cancer is the fifth leading cause of cancer death in men and women. Only 1 out of 4 patients will live 1 year after the cancer is found and only 1 out of 25 will survive five or more years.

The National Cancer Institute (NCI) has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI and NIDDK.

IRRITABLE BOWEL SYNDROME (IBS)

IBS is a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis. Once a diagnosis of IBS is made, medical treatment is limited because the medical community still does not understand the pathophysiology of the underlying conditions.

Living with IBS is a challenge, patients face a life of learning to manage a chronic illness that is accompanied by pain and unrelenting gastrointestinal symptoms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. IBS is an unpredictable disease. A patient can wake up in the morning feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. The DDNC recommends that NIDDK increase its research portfolio on Functional Gastrointestinal Disorders and Motility Disorders.

DIGESTIVE DISEASE COMMISSION

In 1976, Congress enacted Public Law 94-562, which created a National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the U.S., identifying areas in which improvement in the management of digestive diseases can be accomplished and to create a long-range plan to recommend resources to effectively deal with such diseases.

The DDNC recognizes the creation of the National Commission on Digestive Diseases, and looks forward to working with the National Commission to address the numerous digestive disorders that remain in today's diverse population.

CONCLUSION

The DDNC understands the challenging budgetary constraints and times we live in that this subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program at NIH and CDC. Millions of Americans are pinning their hopes for a better life, or even life itself, on digestive disease research conducted through the National Institutes of Health. Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014

- 1) \$32 billion for the National Institutes of Health (NIH) and proportional increases across its institutes and centers.
- 2) Continue to support the Dystonia Coalition Within the Rare Disease Clinical Research Network (RDCRN) coordinated by the Office of Rare Diseases Research (ORDR) in the National Center for Advancing Translational Sciences (NCATS).

- 3) Expand dystonia research supported by NIH through the National Institute on Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD) and the National Eye Institute (NEI).

Dystonia is a neurological movement disorder characterized by involuntary muscle spasms that cause the body to twist, repetitively jerk, and sustain postural deformities. Focal dystonia affects specific parts of the body, while generalized dystonia affects multiple parts of the body at the same time. Some forms of dystonia are genetic but dystonia can also be caused by injury or illness. Although dystonia is a chronic and progressive disease, it does not impact cognition, intelligence, or shorten a person's life span. Conservative estimates indicate that between 300,000 and 500,000 individuals suffer from some form of dystonia in North America alone. Dystonia does not discriminate, affecting all demographic groups. There is no known cure for dystonia and treatment options remain limited.

Although little is known regarding the causes and onset of dystonia, two therapies have been developed that have demonstrated a great benefit to patients and have been particularly useful to controlling patient symptoms. Botulinum toxin (e.g., Botox, Xeomin, Disport and Myobloc) injections and deep brain stimulation have shown varying degrees of success alleviating dystonia symptoms. Until a cure is discovered, the development of management therapies such as these remains vital, and more research is needed to fully understand the onset and progression of the disease in order to better treat patients.

DYSTONIA RESEARCH AT THE NATIONAL INSTITUTES OF HEALTH (NIH)

Currently, dystonia research supported by NIH is conducted through the National Institute of Neurological Disorders and Stroke (NINDS), the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Eye Institute (NEI), and the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS).

ORDR coordinates the Rare Disease Clinical Research Network (RDCRN) which provides support for studies on the natural history, epidemiology, diagnosis, and treatment of rare diseases. RDCRN includes the Dystonia Coalition, a partnership between researchers, patients, and patient advocacy groups to advance the pace of clinical research on cervical dystonia, blepharospasm, spasmodic dysphonia, craniofacial dystonia, and limb dystonia. The Dystonia Coalition has made tremendous progress in preparing the patient community for clinical trials as well as funding promising studies that hold great hope for advancing our understanding and capacity to treat primary focal dystonias. DAN urges the subcommittee to continue its support for the Dystonia Coalition, part of the Rare Disease Clinical Research Network coordinated by ORDR within NCATS.

The majority of dystonia research at NIH is conducted through NINDS. NINDS has utilized a number of funding mechanisms in recent years to study the causes and mechanisms of dystonia. These grants cover a wide range of research including the genetics and genomics of dystonia, the development of animal models of primary and secondary dystonia, molecular and cellular studies in inherited forms of dystonia, epidemiology studies, and brain imaging. DAN urges the subcommittee to support NINDS in conducting and expanding critical research on dystonia.

NIDCD and NEI also support research on dystonia. NIDCD has funded many studies on brainstem systems and their role in spasmodic dysphonia, or laryngeal dystonia. Spasmodic dysphonia is a form of focal dystonia which involves involuntary spasms of the vocal cords causing interruptions of speech and affecting voice quality. NEI focuses some of its resources on the study of blepharospasm. Blepharospasm is an abnormal, involuntary blinking of the eyelids which can render a patient legally blind due to a patient's inability to open their eyelids. DAN encourages partnerships between NINDS, NIDCD and NEI to further dystonia research.

In summary, DAN recommends the following for fiscal year 2014:

- \$32 billion for NIH and a proportional increase for its Institutes and Centers.
- Support for the Dystonia Coalition within the Rare Diseases Clinical Research Network coordinated by ORDR within NCATS.
- Expansion of the dystonia research portfolio at NIH through NINDS, NIDCD, NEI, and ORDR.

THE DYSTONIA ADVOCACY NETWORK

The Dystonia Medical Research Foundation (DMRF) submits these comments on behalf of the Dystonia Advocacy Network (DAN), a collaborative network of five patient organizations: the Benign Essential Blepharospasm Research Foundation, the

Dystonia Medical Research Foundation, the National Spasmodic Dysphonia Association, the National Spasmodic Torticollis Association, and ST/Dystonia, Inc. DAN advocates for all persons affected by dystonia and supports a legislative agenda that meets the needs of the dystonia community.

DMRF was founded over 33 years ago. Since its inception, the goals of DMRF have remained to advance research for more effective treatments of dystonia and ultimately find a cure; to promote awareness and education; and support the needs and well being of affected individuals and their families.

Thank you for the opportunity to present the views of the dystonia community, we look forward to providing any additional information.

PREPARED STATEMENT OF THE ELDERCARE WORKFORCE ALLIANCE

Mr. Chairman, Ranking Member Moran, and members of the subcommittee: We are writing on behalf of the Eldercare Workforce Alliance (EWA), which is comprised of 28 national organizations united to address the immediate and future workforce crisis in caring for an aging America. As the subcommittee begins consideration of funding for programs in fiscal year 2014, the Alliance¹ urges you to provide adequate funding for programs designed to increase the number of health care professionals prepared to care for America's growing senior population and to support family caregivers in the essential role they play in this regard.

Today's health care workforce is inadequate to meet the special needs of older Americans, many of whom have multiple chronic physical and mental health conditions and cognitive impairments. It is estimated that an additional 3.5 million trained health care workers will be needed by 2030 just to maintain the current level of access and quality. Without a national commitment to expand training and educational opportunities, the workforce will be even more constrained in its ability to care for the growth in the elderly population as the baby boom generation ages. Reflecting this urgency, the Health Resources and Services Administration (HRSA) has identified "enhancing geriatric/elder care training and expertise" as one of its top five priorities.

Of equal importance is supporting the legions of family caregivers who annually provide billions of hours of uncompensated care that allows older adults to remain in their homes and communities. The estimated economic value of family caregivers' unpaid care was approximately \$450 billion in 2009.

The number of Americans over age 65 is expected to reach 70 million by 2030, representing a 71 percent increase from today's 41 million older adults. That is why Title VII and Title VIII geriatrics programs and Administration on Aging (AoA) programs that support family caregivers are so critical to ensure that there is a skilled eldercare workforce and knowledgeable, well-supported family caregivers available to meet the complex and unique needs of older adults.

We hope you will support a total of \$47.4 million in funding for geriatrics programs in Title VII and Title VIII of the Public Health Service Act and \$173 million in funding for programs administered by the Administration on Aging that support the vital role of family caregivers in providing care for older adults. Specifically, we recommend the following levels:

- \$42.4 million for Title VII Geriatrics Health Professions Programs;
- \$5 million for Title VIII Comprehensive Geriatric Education Programs; and
- \$173 million for Family Caregiver Support Programs.

Geriatrics health profession training programs are integral to ensuring that America's healthcare workforce is prepared to care for the Nation's rapidly expanding population of older adults. In light of current fiscal constraints, EWA specifically requests \$47.4 million in funding for the following programs administered through the Health Resources and Services Administration (HRSA) under Title VII and VIII of the Public Health Service Act.

Title VII: Geriatrics Health Professions
Appropriations Request: \$42.4 Million

Title VII Geriatrics Health Professions programs are the only Federal programs that seek to increase the number of faculty with geriatrics expertise in a variety of disciplines. These programs offer critically important training for the healthcare workforce overall to improve the quality of care for America's elders.

¹ The positions of the Eldercare Workforce Alliance reflect a consensus of 75 percent or more of its members. This testimony reflects the consensus of the Alliance and does not necessarily represent the position of individual Alliance member organizations.

- Geriatric Academic Career Awards (GACA)*.—The goal of this program is to promote the development of academic clinician educators in geriatrics. Program Accomplishments: In the Academic Year 2011–2012, the GACA program funded 66 full-time junior faculty. These awardees delivered over 1,000 interprofessional continuing education courses specific to geriatric-related topics to over 44,000 students and providers. Collectively, awardees of the program provided a total of 32,000 hours of instruction through continuing education courses. Additionally, they provided 4,700 clinical trainings to providers of many professions and disciplines throughout the academic year. HRSA, through the Affordable Care Act (ACA), expanded the awards to be available to more disciplines. EWA strongly supports this expansion and requests adequate funding to make it possible. Currently, new awardees are selected only every 5 years. To meet the need for clinician educators in all disciplines, EWA believes that awards should be made available to clinical educators annually in order to develop adequate numbers of faculty to provide geriatric instruction and training. EWA's fiscal year 2014 request of \$5.5 million will support current GAC Awardees in their development as clinician educators.
- Geriatric Education Centers (GEC)*.—The goal of Geriatric Education Centers is to provide high quality interprofessional geriatric education and training to current members of the health professions workforce, including geriatrics specialists and non-specialists. Program Accomplishments: In Academic Year 2011–2012, the 45 GEC grantees developed and provided over 4,100 continuing education and clinical training offerings to nearly 80,000 health professionals, students, faculty, and practitioners, significantly exceeding the program's performance target. Three quarters of the continuing education offerings were interprofessional in focus. Of the sites that offered clinical training sessions, almost 75 percent of these sites were in a medically underserved community and/or Health Professional Shortage Area. The GECs provide much needed education and training. As part of the ACA, Congress authorized a supplemental grant award program that will train additional faculty through a mini-fellowship program. The program provides training to family caregivers and direct care workers. Our funding request of \$22.7 million includes support for the core work of 45 GECs and \$2.7 million for awards to 24 GECs that would be funded to undertake the development of mini-fellowships under the supplemental grants program included in ACA.
- Alzheimer's Disease Prevention, Education, and Outreach Program (GECs)*.—These funds, included in the President's fiscal year 2014 budget request, will allow HRSA to expand efforts to provide training to healthcare providers on Alzheimer's disease and related dementias, utilizing the already existing Geriatric Education Centers (GECs). EWA Requests \$5.3 million.
- Geriatric Training Program for Physicians, Dentists, (GTPD) and Behavioral and Mental Health Professions*.—The goal of the GTPD program is to increase the number and quality of clinical faculty with geriatrics and cultural competence, including retraining mid-career faculty in geriatrics. Program Accomplishments: In Academic Year 2011–2012, a total of 63 physicians—including psychiatrists-, dentists, and psychologists, were supported through this fellowship program. During that year alone, fellows provided geriatric care to older adults on 23,358 occasions. This program supports training additional faculty in medicine, dentistry, and behavioral and mental health so that they have the expertise, skills, and knowledge to teach geriatrics and gerontology to the next generation of health professionals in their disciplines. EWA's funding request of \$8.9 million will support 12 institutions to continue this important faculty development program.

Title VIII Geriatrics Nursing Workforce Development Programs
 Appropriations Request: \$5 million

Title VIII programs, administered by the HRSA, are the primary source of Federal funding for advanced education nursing, workforce diversity, nursing faculty loan programs, nurse education, practice and retention, comprehensive geriatric education, loan repayment, and scholarship.

- Comprehensive Geriatric Education Program*.—The goal of this program is to provide quality geriatric education and training to individuals caring for the elderly. Program Accomplishments: In Academic Year 2011–2012, a total of 18 Comprehensive Geriatric Education Program (CGEP) grantees provided a variety of services, including over 1,700 hours of instruction to over 8,200 trainees. Topics included geriatric training for direct care providers, palliative and end-of-life care, and health care and older adults. This program supports additional training for nurses who care for the elderly; development and dissemination of

curricula relating to geriatric care; training of faculty in geriatrics; and continuing education for nurses practicing in geriatrics.

—*Traineeships for Advanced Practice Nurses.*—Through the ACA, the Comprehensive Geriatric Education Program is being expanded to include advanced practice nurses who are pursuing long-term care, geropsychiatric nursing, or other nursing areas that specialize in care of older adults. EWA's funding request of \$5 million will support the education and training of individuals who provide geriatric care.

Administration on Aging: Family Caregiver Support
Appropriations Request: \$172.9 million

These programs support caregivers, elders, and people with disabilities by providing critical respite care and other support services for family caregivers, training and recruitment of care workers and volunteers, information and outreach, counseling, and other supplemental services.

Family Caregiver Support Services.—This program provides a range of support services to approximately 700,000 family and informal caregivers annually in States, including counseling, respite care, training, and assistance with locating services that assist family and informal caregivers in caring for their loved ones at home for as long as possible. EWA requests \$154.5 million.

Native American Caregiver Support.—This program provides a range of services to Native American caregivers, including information and outreach, access assistance, individual counseling, support groups and training, respite care and other supplemental services. EWA requests \$6.4 million.

Alzheimer's Disease Support Services.—One critical focus of this program is to support the family caregivers who provide countless hours of unpaid care, thereby enabling their family members with dementia to continue living in the community. Funds will go towards evidence-based interventions and expand the dementia-capable home and community-based services, enabling additional older adults to live in their residence of choice. EWA requests \$9.5 million.

Lifespan Respite Care.—This program funds grants to improve the quality of and access to respite care for family caregivers of children or adults of any age with special needs. EWA requests \$2.5 million.

On behalf of the members of the Eldercare Workforce Alliance, we commend you on your past support for geriatric workforce programs and ask that you join us in supporting the geriatrics workforce at this critical time—for all older Americans deserve quality care, now and in the future. Thank you for your consideration.

PREPARED STATEMENT OF THE ENDOCRINE SOCIETY

The Endocrine Society is pleased to submit the following testimony regarding fiscal year 2014 Federal appropriations for biomedical research, with an emphasis on appropriations for the National Institutes of Health (NIH). The Endocrine Society is the world's largest and most active professional organization of endocrinologists representing more than 16,000 members worldwide. Our organization is dedicated to promoting excellence in research, education, and clinical practice in the field of endocrinology. The Society's membership includes thousands of researchers who depend on Federal support for their careers and their scientific advances. The Endocrine Society recommends that NIH receive at least \$32 billion in fiscal year 2014. This funding recommendation represents the minimum investment necessary to avoid further erosion of national research priorities and global preeminence, while allowing the NIH's budget to keep pace with biomedical inflation.

A half century of sustained investment by the United States Federal Government in biomedical research has dramatically advanced the health and improved the lives of the American people. The NIH specifically has had a significant impact on the United States' global preeminence in research and fostered the development of a biomedical research enterprise that remains unrivaled throughout the world. However, the preeminence of the U.S. research enterprise is being tested due to consistently flat funding for Federal research agencies coupled with the increasing cost of conducting basic biomedical research. Meanwhile, emerging economies such as China and India continue to recognize the importance of investing in scientific research. China's R&D spending is expected to increase by 11.6 percent in the coming year while India's spending for R&D is expected to rise by nearly 12 percent, keeping pace with the past several years.¹

¹“Global R&D Funding Forecast 2013.” Battelle.

The societal benefits of biomedical research, from improvements in diabetes care to personalized genomics, include treatments, technologies, and cures that extend lifespan and improve quality of life. The foundation for these benefits is the NIH research grants that support the basic research done by scientists. Since 2004, the number of NIH research grants to scientists in the United States has been declining. Consequently, the likelihood of a scientist successfully being awarded a grant has dropped from 31.5 percent in 2000 to 17.6 percent in 2012; this means that experienced scientists are increasingly spending time writing fruitless grant applications instead of applying their expertise to productive research. Meanwhile younger, highly skilled Ph.D. holders struggle to find a job in the United States that makes use of the unique skills generated during graduate education. The Chinese Government, in contrast, has created incentives to draw biomedical researchers to institutions in China.² The potential loss of technical skills and knowledge generated by the investment of resources in training could reduce the long-term international competitiveness of the United States and result in innovative new biomedical therapeutics being developed in other countries.

The United States cannot afford to fall further behind while the rising burden of chronic disease (now at 75 percent of total healthcare expenditure) places a tremendous strain on the national economy. Nearly half of all Americans have a chronic medical condition, and these diseases now cause more than half of all deaths worldwide. Deaths attributed to chronic conditions could reach 36 million by 2015 if the trend continues unabated. In order to prevent and treat these diseases, and save the country billions in healthcare costs, significant investment in biomedical research will be needed. The national cost of diabetes in 2012 is estimated at \$245 billion,³ while the cost of obesity has been estimated at \$147 billion;⁴ many Endocrine Society members study these diseases and stand ready to conduct valuable research to improve care and reduce the financial burden of disease. To do so, however, they require funding from the NIH.

Besides improving healthcare delivery and reducing costs, basic biomedical research represents a source of new wealth for the Nation and jobs for its citizens. The translation of new knowledge into innovative products can be shown by the frequency in which patents are granted to University researchers. Data compiled by the Association of University Technology Managers (AUTM) shows that academic research institutions were issued 4,700 patents in 2011. These patents can then be used to form the intellectual property foundation for a startup, or licensed to a large company to generate future revenue streams from the patented technology. In 2011, AUTM reported 4899 university technologies were licensed to companies, demonstrating the potential economic value of the products of federally-funded basic research to private companies. Basic research at academic universities and research institutions, funded in part by NIH, generated 617 startup companies and 591 new commercial products in 2011 alone. AUTM also reported \$36 billion in net product sales generated from university-initiated companies, while recent startups reported supporting nearly 25,000 jobs. From 1996 to 2007, a “moderately conservative estimate” yields a total contribution to GDP for this period of more than \$82 billion⁵ from university technologies.

Because the financial risks associated with basic biomedical research projects are high, and the economic realization of an investment in biomedical research could take years to decades, private sector businesses are unlikely to make the financial commitments necessary to support basic biomedical research. The private sector, in fact, “cannot appropriate the benefits such research generates, particularly at the early, basic stages of the research process.”⁶ Consequently, the private sector investment in basic science represents only 20 percent of the total national investment. While the private sector investment in applied research and development is much greater, basic research represents the crucial first step in the process of developing an innovative biomedical product. Indeed, Congress has acknowledged the critical

²“Building a World-Class Innovative Therapeutic Biologics Industry in China”—China Association of Enterprises with Foreign Investment R&D-based Pharmaceutical Association Committee, in coordination with The Biotechnology Industry Organization and the support of The Boston Consulting Group.

³“Economic Costs of Diabetes in the U.S. in 2012”—American Diabetes Association.

⁴Finkelstein, EA, Trogon, JG, Cohen, JW, and Dietz, W. “Annual medical spending attributable to obesity: Payer- and service-specific estimates.” *Health Affairs* 2009; 28(5): w822-w831.

⁵“The Economic Impact of Licensed Commercialized Inventions Originating in University Research, 1996–2007.” Biotechnology Industry Organization, September 2009.

⁶“An Economic Engine: NIH Research, Employment and the Future of the Medical Innovation Sector.” United for Medical Research, May 2011.

and unique role of the Government in funding basic research to realize the unique and powerful economic benefits to society.⁷

The past year alone has seen astonishing medical breakthroughs from NIH funded research, such as advances in HIV prevention and genomic characterization of cancer cells. Endocrinologists have made discoveries on the link between birth order and diabetes risk, the generational effects of BPA exposure, and the relationship between a mother's vitamin D levels and infant health. A member of The Endocrine Society, Robert Lefkowitz, was one of two recipients of the 2012 Nobel Prize in Chemistry for his work on hormone receptors. The NIH has exciting programs for the future, including a collaboration to develop "3-D human tissue chips containing bio-engineered tissue models that mimic human physiology . . . to use these chips to better predict the safety and effectiveness of candidate drugs."⁸ Members of The Endocrine Society will continue to conduct important work, including research on the public health impact of chronic disease and endocrine-disrupting chemicals. These projects, however, may not come to fruition if the current NIH budget, and the cut from sequestration, remain in place.

The direct effects of the cut to the NIH and NSF budgets from sequestration are now just beginning to manifest after 2 months. Stories are emerging about how sequestration will delay, or stop entirely, research projects critical to our understanding of disease and prevention. Endocrine Society member Rebecca Riggins, Ph.D., has been forced to delay indefinitely an analysis of tumor samples to investigate why certain types of breast cancer respond differently to treatment with Tamoxifen.⁹ Sequestration is also forcing universities such as Vanderbilt University and the University of Florida, who stand to lose millions in Federal research dollars, to reduce the number of graduate students accepted into Ph.D. programs for the upcoming academic year.^{10 11} Stories such as these will become more common unless the Federal Government acts to prioritize the national investment in basic research in fiscal year 2014.

The Endocrine Society remains deeply concerned about the future of biomedical research in the United States without sustained support from the Federal Government. Flat funding in recent years, combined with the impact of sequestration, threaten the Nation's scientific enterprise and make the fiscal year 2014 appropriations for agencies that fund science increasingly important. The Society strongly supports increased Federal funding for biomedical research in order to provide the additional resources needed to enable American scientists to address scientific opportunities and maintain the country's status of the preeminent research enterprise. The Endocrine Society therefore recommends that NIH receive at least \$32 billion in fiscal year 2014.

PREPARED STATEMENT OF THE EPILEPSY FOUNDATION OF AMERICA

Thank you, Chairman Harkin and Ranking Member Moran, for allowing me to testify on behalf of the more than 2.2 million Americans living with epilepsy and their families, including my own. Specifically, I want to express my support for continued funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), as well as funding for epilepsy research at the National Institutes of Health.

Epilepsy is the Nation's fourth most common neurological disorder, after migraine, stroke, and Alzheimer's disease; making it an important public health condition. Epilepsy is a complex spectrum of disorders—sometimes called the epilepsies—that affects millions of people in a variety of ways and is characterized by unpredictable seizures that differ in type, cause, and severity. Yet living with epilepsy is about much more than just seizures. For people with epilepsy, the disorder is often

⁷ "The Pivotal Role of Government Investment in Basic Research—Report by the U.S. Congress Joint Economic Committee." May 2010.

⁸ <http://www.ncats.nih.gov/research/reengineering/tissue-chip/funding/funding.html> (accessed March 12, 2013).

⁹ Marder, J., "Sequester Cuts to Science Slow Biomedical Research." PBS Newshour, Science Wednesday, April 3, 2013. <http://www.pbs.org/newshour/rundown/2013/04/sequester-cuts-to-science-puts-medical-research-on-hold.html> (Accessed April 25, 2013).

¹⁰ Smith-Barrow, D., "What Graduate Students Should Know About the Sequester." U.S. News, April 1, 2013. <http://www.usnews.com/education/best-graduate-schools/articles/2013/04/01/what-graduate-students-should-know-about-the-sequester> (Accessed April 24, 2013).

¹¹ Schweers, J., "UF's flow of research dollars may slow to trickle." The Gainesville Sun, March 30, 2013. <http://www.gainesville.com/article/20130330/ARTICLES/130339981?p=1&tc=pg> (Accessed April 25, 2013).

defined in practical terms, such as challenges in school, uncertainties about social situations and employment, limitations on driving, and questions about independent living. Approximately 1 in 26 people will develop epilepsy at some point in their lives, and the onset of epilepsy is highest in children and older adults.

In October, 2012, the Epilepsy Foundation began a merger with the Epilepsy Therapy Project to create a unified organization driving education, awareness, support, and new therapies for people and families living with epilepsy. This merger became effective on January 1st and brings together the mission and assets of both organizations, including www.epilepsy.com, the leading portal for people, caregivers, and professionals dealing with epilepsy; 47 affiliated Epilepsy Foundations around the country dedicated to providing free programs and services to people living with epilepsy and their loved ones; scientific, professional, and business advisory boards comprised of leading epilepsy physicians, health care professionals and researchers, industry professionals, and investors with experience in clinical care, as well as in the evaluation and commercialization of new therapies; a track record of identifying and supporting important new science, translational research programs, and the most promising new therapies; and the Epilepsy Pipeline Conference, a leading global forum organized in partnership with the Epilepsy Study Consortium that showcases the most exciting new drugs, devices, and therapies.

The Epilepsy Foundation has long realized that epilepsy should be a priority for the Federal public health system, and that public health programs can help build safer communities, end stigma and discrimination associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions. Stigma surrounding epilepsy continues to fuel discrimination and isolates people with epilepsy from the mainstream of life. Among older children and adults, epilepsy remains a formidable barrier to educational opportunities, employment, and personal fulfillment. There is a continuing need to better understand the public health impact of the condition, promote initiatives that encourage self-management, and improve mental health. Meeting these needs will help create an environment in which people will feel free to disclose their epilepsy or seizures without fear of discrimination or reprisal.

The Epilepsy Foundation was pleased to participate in the 2012 Institute of Medicine report: *Epilepsy Across the Spectrum: Promoting Health and Understanding*. We believe that many of the 13 recommendations from the report reinforce the need for public health programs that help people with epilepsy access the best care and the importance of a health care workforce that is educated about seizures and epilepsy.

The CDC is the lead Federal agency for protecting the people's health and safety. It is responsible for providing credible information to enhance health decisions and for promoting health through strong partnerships. The 2012 Institute of Medicine report calls upon the CDC to continue and expand collaborative surveillance and data collection, and we strongly support this recommendation to improve epilepsy surveillance within the CDC. The report also calls on the CDC to work with the Epilepsy Foundation and its affiliates to enhance educational and community services for people with epilepsy.

The CDC epilepsy program focuses on better understanding the epidemiology and impacts of epilepsy, developing and bringing interventions to the public that improve quality of life for people with epilepsy, and working with partners to change systems and environments to better support those living with this neurological condition. CDC collaborates with partners to improve public awareness and promote education and communication at local and national levels. Programs focus on law enforcement and emergency medical responders, school-based students and staff, seniors, unemployed and underemployed adults, and underserved minorities living with epilepsy.

The Epilepsy Foundation strongly believes that not only should the CDC program maintain its current funding to continue the quality programs that help address care and eliminate stigma, but also that it should receive additional funding to fulfill the recommendations and the investment of the IOM report and take advantage of the research and guidance that the report provides.

HRSA directs national health programs that improve the Nation's health by assuring equitable access to comprehensive quality health care for all. HRSA promotes a community-based system of services mandated for all children with special health care needs; supports programs that are designed to break down barriers to community living for people with disabilities; and provides primary health care to medically underserved people. The 2012 Institute of Medicine report also calls upon stakeholders like the Foundation and HRSA to identify needs and improve community services for underserved populations. We believe that Project Access is an important part of meeting that goal and fully support the work of HRSA to empower

families in health decisionmaking, promote medical home models, support access to health care, increase early health care screenings, and facilitate transition for youth to improved healthy and independent lives.

Project Access is a national effort which involves State agencies, physicians and other health care providers, families, schools, and community resources to implement demonstration projects in medically underserved areas to improve health care outcomes and access for children with epilepsy. Demonstration projects have been conducted in California, Washington, D.C., Wisconsin, New Jersey, Mississippi, Illinois, West Virginia, Alaska, Nevada, Wyoming, Washington, New Hampshire, Maine, Florida, New York and Oregon. These projects not only serve needs of an important public health condition like epilepsy, but can serve as a model for other chronic health conditions and disabilities.

The Epilepsy Foundation understands the financial constraints facing our Nation today. We encourage Congress to continue funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention and the Health Resources and Services Administration. We also urge Congress to not abandon research initiatives that have been partially funded at the National Institutes of Health, and to support funding for a cure and better treatments for epilepsy.

Thank you for your consideration of this critical issue.

PREPARED STATEMENT OF THE FEDERATION OF AMERICAN SOCIETIES FOR
EXPERIMENTAL BIOLOGY

The Federation of American Societies for Experimental Biology (FASEB) respectfully requests a fiscal year 2014 appropriation of no less than \$32 billion for the National Institutes of Health (NIH) to prevent further erosion of the Nation's capacity for biomedical research and provide funding for additional grantees.

As a federation of 26 scientific societies, FASEB represents more than 100,000 life scientists and engineers, making it the largest coalition of biomedical research associations in the United States. FASEB's mission is to advance health and welfare by promoting progress and education in biological and biomedical sciences, including the research funded by NIH, through service to its member societies and collaborative advocacy. FASEB enhances the ability of scientists and engineers to improve—through their research—the health, well-being, and productivity of all people.

Research funded by the National Institutes of Health (NIH) has produced an outstanding legacy, and American leadership in biomedical research has made us the envy of the world. Eighty-five percent of NIH funds are distributed through competitive grants to more than 300,000 scientists who work at universities, medical schools, and other research institutions in nearly every congressional district in the United States. NIH researchers developed the first screening test that reduced mortality from lung cancer, sponsored clinical trials to significantly reduce transmission of Human Immunodeficiency Virus from mother to child, uncovered the precise cause of more than 4,500 rare diseases, and completed a ten-year diet and exercise study showing how we can reduce the incidence of type 2 diabetes among high-risk people by more than 30 percent. Many of these advances arose from investigations designed to explain basic molecular, cellular, and biological mechanisms.

More recently, NIH has supported research that led to breakthroughs in:

—*Preventing Colon Cancer Deaths.*—A study funded primarily by the National Cancer Institute found that removing polyps (abnormal growths) during colonoscopy can not only prevent colorectal cancer, but also reduce the chance of death from the disease by 53 percent. Colorectal cancer is one of the most common cancers in both men and women nationwide and colonoscopies can detect early-stage cancer before symptoms develop, allowing doctors to remove any polyps. Early detection is important because treatments are more likely to succeed if the disease is caught before it takes hold. This study provides strong evidence of the long-term benefit of removing polyps and supports continued screening for colorectal cancer in individuals over age 50.

—*Offering New Hope For Children With An Immunodeficiency Disorder.*—Researchers supported by the National Human Genome Research Institute and the National Heart, Lung and Blood Institute discovered that gene therapy can safely restore immune function in children with severe combined immunodeficiency (SCID), a disorder that leaves patients susceptible to a wide range of infections because they cannot produce healthy white blood cells. Most children with SCID die by the age of two if left untreated. Previously available treatments relied on expensive enzyme replacement injections that had to be continued throughout the child's life. A clinical trial found that gene therapy

using the patient's own stem cells and low-dose chemotherapy was effective in eliminating the need for enzyme replacement therapy and leading to long-term improved health. A second phase of the trial is now underway.

—*Repurposing Older Drugs to Treat Alzheimer's.*—Bexarotene, a drug that has been available for 10 years to treat skin cancer, rapidly reduced beta-amyloid levels in the brains of mice of all ages and shrank amyloid deposits known as plaques in most age groups. Abnormally high levels of beta-amyloid have been found in the brains of individuals with the most common, late-onset form of Alzheimer's disease. This NIH-funded study also found that Bexarotene restored cognition and memory in mice and improved the animals' ability to sense and respond to odors. Loss of smell is often a first symptom of Alzheimer's in humans.

Sustained Funding is Critical in Order to Capitalize on New Scientific Opportunities

The broad program of research supported by NIH is essential for advancing our understanding of basic biological functions, reducing human suffering, and protecting the country against new and re-emerging disease threats. Biomedical research is also a primary source of new innovations in health care and other areas.

Exciting new NIH initiatives are poised to accelerate our progress in the search for cures. It would be tragic if we could not capitalize on the many opportunities before us. The development of a universal vaccine to protect adults and children against both seasonal and pandemic flu and development of gene chips and DNA sequencing technologies that can predict risk for high blood pressure, kidney disease, diabetes, and obesity are just a few of the research breakthroughs that will be delayed if we fail to sustain the investment in NIH.

As a result of our prior investment, we are the world leader in biomedical research. We should not abdicate our competitive edge. Without adequate funding, NIH will have to sacrifice valuable lines of research. The termination of ongoing studies and the diminished availability of grant support will result in the closure of laboratories and the loss of highly skilled jobs. At a time when we are trying to encourage more students to pursue science and engineering studies, talented young scientists are being driven from science by the disruption of their training and lack of career opportunities.

Rising costs of research, the increasing complexity of the scientific enterprise, and a loss of purchasing power at NIH due to flat budgets have made it increasingly competitive for individual investigators to obtain funding. In addition, the \$1.6 billion in cuts to NIH due to the sequestration mandated by the Budget Control act will exacerbate the current challenges facing the research community. Today, only one in six grant applications will be supported, the lowest rate in NIH history. Increasing the NIH budget to \$32.0 billion would provide the agency with an additional \$1.360 billion which could restore funding for R01 grants (multi-year awards to investigators for specified projects) back to the level achieved in 2003 and support an additional 1,700 researchers while still providing much needed financial support for other critical areas of the NIH portfolio.

Federal Investment in Research is Essential to Drive Innovation in the Private Sector

The Federal Government has a unique role in supporting research. Scientists and engineers in every State are hard at work creating the knowledge that will improve health, energy independence, agricultural productivity, and provide the foundation for new industries.¹ No other public, corporate or charitable entity is willing or able to provide broad and sustained funding for cutting edge science and engineering that will yield new innovations and technologies of the future. This is particularly critical for basic research, which is the source of profound and paradigm-shifting discoveries. While we are certain such discoveries will be made, there are no signposts for where and when the next major breakthrough will occur. The breadth of investment required has become too daunting for most of the commercial companies that develop new products from findings from investments in fundamental research, to say nothing of those enterprises yet to be created.

To prevent further erosion of the Nation's capacity for biomedical research, FASEB recommends an appropriation of no less than \$32.0 billion for NIH in fiscal year 2014 to ensure the stability of the research enterprise and provide funding for additional grantees.

¹ www.faseb.org/NIHfactsheets

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE OF CHILD
HEALTH AND HUMAN DEVELOPMENT

My name is Kathryn Schubert. I currently serve as Chair of the Friends of the National Institute of Child Health and Human Development (NICHD). On behalf of the Friends, I urge the Labor, Health and Human Services, Education Appropriations Subcommittee to support at least \$32 billion for the NIH, including \$1.37 billion for NICHD for fiscal year 2014. Our coalition includes over 100 organizations representing scientists, physicians, health care providers, patients and parents concerned with the health and welfare of women, children, families, and people with disabilities. We are pleased to support the extraordinary work of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD).

Since its establishment in 1963, NICHD has achieved great success in meeting the objectives of its broad biomedical and behavioral research mission, which includes research on child development before and after birth; maternal, child, and family health; learning and language development; reproductive biology and population issues; and medical rehabilitation. With sufficient resources, NICHD could build upon the promising initiatives described in this testimony and produce new insights into human development and solutions to health and developmental problems throughout the world, including families in your districts. Scientific breakthroughs supported by NICHD serve to prevent and treat many of the Nation's most devastating health problems including infant mortality and low birthweight, birth defects, intellectual and developmental disabilities, and the reproductive and gynecologic health of women throughout their lifespan, among others. Some of these are described below.

Preterm Birth.—NICHD supports a comprehensive research program to study the causes of preterm birth and prevention strategies and treatment regimens. Pre-term birth costs our Nation \$26 billion annually and is a leading cause of infant mortality and intellectual and physical disabilities. Continued prioritization of extramural preterm birth prevention research, the Maternal-Fetal Medicine Units Network, the Neonatal Research Network and intramural research program related to prematurity are necessary to further this work. Resources also should be available to support transdisciplinary science as recommended in NICHD's Scientific Vision to study and identify the complex causes of preterm birth.

Newborn Screening.—Millions of babies in the U.S. are routinely screened for conditions that can affect a child's long-term health or survival each year. Early detection, diagnosis, and intervention can prevent death or disability. NICHD's newborn screening program aims to identify additional conditions to screen for, develop and test better ways to screen for conditions, study treatments and ways to improve outcomes, and sponsor research and training programs related to newborn screening. These initiatives are accelerating research in diseases related to newborn screening and greatly improving the process by which public health decisions are made.

National Children's Study (NCS).—The NCS is the largest and most comprehensive study of children's health and development ever planned in the United States. We thank the Committee for funding the NCS through the NIH Office of the Director and urge funding at the current level, which will allow for a science-based study design and recruitment strategy for roll-out of the main study. When fully implemented, the NCS will follow a representative sample of 100,000 children from across the U.S. from before birth until age 21, and data generated will inform the work of scientists in universities and research organizations, helping them identify precursors to disease and to develop new strategies for prevention and treatment.

Brain Development.—Research on learning disabilities—neurological disorders that can make it difficult to acquire certain academic and social skills—shows that they can be prevented through effective evidence-based programs in school and that when children improve their reading and math skills, brain function normalizes.

Behavioral Research.—We support and commend the advances NICHD has made in examining normative child development and the critical impact of stress in altering a child's developmental trajectories. Recent discoveries show that chronic stress from a number of factors including poverty, exposure to violence, child maltreatment and neglect and ethnic minority status may all hamper a child's potential to optimize their social and emotional development and academic achievement. Sufficient resources could go toward longitudinal research that is needed to understand the long-term impact of stress on mental health outcomes, cognitive, emotional and social development, including self-control, inhibitory response, executive functioning, attention, memory and learning skills and how those variables impact later adolescent health behaviors, childhood obesity and academic achievement.

Contraceptive Research and Development.—NICHD's leadership in ensuring acceptability and effective use of existing products in various settings and populations

and in addressing behavioral issues related to fertility and contraceptive use will lead to opportunities and priorities in the future, including evaluation of the safety and effectiveness of hormonal contraceptive options for women who are overweight or obese. NICHD contraceptive development is critical for producing new contraceptive modalities that offer couples options with fewer side-effects and address women's concerns about contraceptive use. Opportunities in contraceptive development include the need for non-hormonal contraception, peri-coital contraception and multipurpose prevention technologies that would prevent both pregnancy and sexually transmitted infections.

Reproductive Sciences.—NICHD's research in developing innovative medical therapies and technologies have improved existing treatment options for gynecological conditions affecting overall health and fertility. Future work could focus on serious conditions that have been overlooked and underfunded although they impact many women, such as infertility research into the need for treatments for disorders such as endometriosis, polycystic ovarian syndrome (PCOS) and uterine fibroids which can prevent couples from achieving desired pregnancies.

Pelvic Floor Disorders Network (PFDN).—Female pelvic floor disorders (PFD) represent an under-appreciated but major public health burden with high prevalence, impaired quality of life and substantial economic costs affecting approximately 25 percent of American women. The PFDN is conducting research to improve treatment of these extremely painful gynecological conditions. Current research is aimed at improving female urinary incontinence outcome measures and ensuring high quality patient-centered outcomes.

Development of the Research Workforce.—NICHD's Women's Reproductive Health Research (WRHR) Program and Reproductive Scientist Development Program (RSDP), both aimed at obstetrician-gynecologists to further their education and experience in basic, translational, and clinical research or for those studying cellular and molecular biology and genetics and related fundamental sciences provide training grants to hundreds of researchers and providing new insight into a host of diseases, such as ovarian cancer. Continued investment in medical research is critical to making major scientific advances. Studies show that overall levels of research funding influence career choice, making these investments even more important.

Sudden Unexpected Infant Death (SUID) and Stillbirth.—SUID and stillbirth result in the loss of more than 30,000 babies annually. Unsafe infant sleep environments are the major cause of SUID/SIDS deaths for babies between 1 month and 1 year of age and are largely preventable through educational outreach. We support prioritization of the Institute's newly expanded "Safe to Sleep" Campaign and continued research to discern the physiological basis of vulnerability to SIDS. Opportunities for research into late term unexplained losses and prioritization of prevention related to stillbirth risk factors and indicators such as maternal obesity and fetal growth restriction could be taken by convening an Interagency Consensus Group on Stillbirth to discuss the State of Science.

Eosinophil-Associated Disorders.—These disorders can cause painful, debilitating conditions in children, many of whom are unable to eat normal food due to severe reactions. The NIH Task Force on the Research Needs of Eosinophil-Associated Diseases issued a report earlier this year highlighting the need for studies to improve the diagnosis and treatment of these incurable diseases, in which NICHD can play a leading role.

Children's Cardiomyopathy.—Cardiomyopathy is a chronic disease of the heart muscle, which can be hard to detect or misdiagnosed with tragic outcomes in children. In some cases, sudden cardiac arrest is the first symptom of the disease. NICHD has an opportunity to understand the genetic and environmental causes and to explore drugs specific to children, and to generate public awareness materials.

Best Pharmaceuticals for Children Act (BPCA).—NICHD funds meaningful research into pediatric pharmacology and we urge its continued funding for this along with training the next generation of pediatric clinical investigators. With NICHD's leadership, NIH should improve data collection and reporting related to the numbers of children who participate in NIH-funded trials. Age reporting is currently insufficient to determine if children are appropriately represented in trials pertaining to child health.

Population Research.—The NICHD Population Dynamics branch supports a diverse portfolio of scientific research and research training programs, exploring the social, economic and health-related impacts of population change on families, children, and communities. The branch is well respected for investing wisely in the development of longitudinal, representative surveys, providing scientists with reliable data that can be used to examine the influence of early life course events on long-term health and achievement outcomes in particular. As an example, in 2012, NICHD-supported demographers using data from the Panel Study of Income Dy-

namics survey found that growing up in poor neighborhoods throughout the entire childhood life course can have a devastating effect on educational attainment. In another study, using data from the National Study of Adolescent Health, researchers found that women who are overweight or obese years during the transition from adolescence to adulthood are more likely to later deliver babies with a higher birth weight, putting the next generation at a higher risk of obesity-related health outcomes.

These research efforts have made significant contributions to the well-being of all Americans, but there is still much to discover. We support the NICHD's recently released Scientific Vision and urge you to support NICHD at funding levels that meet current needs for addressing health issues across the lifespan. Thank you for your consideration and we look forward to working with you on these critical issues.

PREPARED STATEMENT OF THE FRIENDS OF THE HEALTH RESOURCES AND SERVICES
ADMINISTRATION

The Friends of HRSA is a non-profit and non-partisan coalition of more than 175 national organizations dedicated to ensuring that our Nation's medically underserved populations have access to high-quality primary and preventive care. The coalition represents millions of public health and health care professionals, academicians and consumers invested in HRSA's mission to improve health and achieve health equity. We recommend funding of at least \$7.0 billion for discretionary HRSA programs in fiscal year 2014.

The recommended funding level takes into account the need to reduce the Nation's deficit while prioritizing the immediate and long-term health needs of Americans. We are deeply concerned with the failure to avert the sequester that will cut over \$311 million from HRSA's fiscal year 2013 discretionary funding. These cuts come on top of the 17 percent or more than \$1.2 billion reduction to HRSA's budget authority since fiscal year 2010. HRSA's ability to prevent sickness, keep people healthy and treat illness or injury for millions of Americans will be severely compromised, by across-the-board cuts if the sequester is not reversed and the cuts restored. It is estimated that 7,400 fewer patients will have access to HRSA's AIDS Drug Assistance Program that provides life-saving HIV medications and about 25,000 fewer breast and cervical cancer screenings will be offered for poor, high-risk women, an important tool to reduce death rates, improve treatment options and greatly increase survival. Our recommended funding level is necessary to ensure HRSA is able to implement essential public health programs including training for public health and health care professionals, providing primary care services through health centers, improving access to care for rural communities, supporting maternal and child health care programs and providing health care to people living with HIV/AIDS.

HRSA is a national leader in providing health services for individuals and families. HRSA's programs are carried out by about 3,100 grantees in every State and U.S. territory, working to improve the health of people who are primarily low-income, medically vulnerable and geographically isolated through access to quality services and a skilled health care workforce. The agency operates about 80 different programs, working to serve roughly 55 million Americans who are uninsured and more than 60 million Americans who live in communities where primary health care services are scarce. In addition to delivering much needed services, the programs provide an important source of local employment and economic growth in many low-income communities.

Our request is based on the need to continue improving the health of Americans by supporting critical HRSA programs including:

- Health professions* programs support the education and training of primary care physicians, nurses, dentists, optometrists, physician assistants, nurse practitioners, clinical nurse specialists, public health personnel, mental and behavioral health professionals, pharmacists and other allied health providers. With a focus on primary care and training in interdisciplinary, community-based settings, these are the only Federal programs focused on filling the gaps in the supply of health professionals, as well as improving the distribution and diversity of the workforce so health professionals are well-equipped to care for the Nation's growing, aging and increasingly diverse population. For example, HRSA offers loan repayment and scholarships to nurses who work in areas experiencing critical shortages of nurses. This investment has increased the number of nurses working in communities with the greatest need by three fold—from about 1,000 to 3,000—since 2008.

- Primary care* programs support nearly 8,900 community health centers and clinics in every State and territory, improving access to preventive and primary care to more than 20 million patients in geographically isolated and economically distressed communities. Close to half of the health centers serve rural populations. The health centers coordinate a full spectrum of health services including medical, dental, behavioral and social services—often delivering the range of services in one location. In addition, health centers target populations with special needs, including migrant and seasonal farm workers, homeless individuals and families and those living in public housing.
- Maternal and child health* programs, including the Title V Maternal and Child Health Block Grant, Healthy Start and others, support a myriad of initiatives designed to promote optimal health, reduce disparities, combat infant mortality, prevent chronic conditions and improve access to quality health care for more than 40 million women and children. Maternal and Child Health Block Grants provide services to 6 out of every 10 women who give birth and their infants. Since Title V was established in 1935, the infant mortality rate has declined nearly 90 percent and contributed to a 51 percent decline in the U.S. child fatality rate from unintentional injuries since 1987. Today, MCH programs help assure that nearly 100 percent of babies born in the U.S. are screened for a range of serious genetic or metabolic diseases and that a community-based system of family centered services is available for coordinated long-term follow up for babies with a positive screen and for all children with special health care needs.
- HIV/AIDS* programs provide the largest source of Federal discretionary funding assistance to States and communities most severely affected by HIV/AIDS. The Ryan White HIV/AIDS Program delivers comprehensive care, prescription drug assistance and support services for more than half a million low-income people impacted by HIV/AIDS, which accounts for roughly half of the total population living with the disease in the U.S. Additionally, the programs provide education and training for health professionals treating people with HIV/AIDS and work toward addressing the disproportionate impact of HIV/AIDS on racial and ethnic minorities.
- Family planning* Title X services ensure access to a broad range of reproductive, sexual and related preventive health care for over 5 million poor and low-income women, men and adolescents at nearly 4,400 health centers nationwide. Health care services include patient education and counseling, cervical and breast cancer screening, sexually transmitted disease prevention education, testing and referral, as well as pregnancy diagnosis and counseling. This program helps improve maternal and child health outcomes and promotes healthy families. Often, Title X service sites provide the only continuing source of health care and education for many individuals.
- Rural health* programs improve access to care for people living in rural areas where there are a shortage of health care services. The Office of Rural Health Policy serves as the Department of Health and Human Services' primary voice for programs and research on rural health issues. Rural Health Outreach and Network Development Grants, Rural Health Research Centers, Rural and Community Access to Emergency Devices Program and other programs are designed to support community-based disease prevention and health promotion projects, help rural hospitals and clinics implement new technologies and strategies and build health system capacity in rural and frontier areas.
- Special programs* include the Organ Procurement and Transplantation Network, the National Marrow Donor Program, the C.W. Bill Young Cell Transplantation Program and National Cord Blood Inventory. These programs maintain and facilitate organ marrow and cord blood donation, transplantation and research, along with efforts to promote awareness and increase organ donation rates. Over the past 20 years, 25,000 individuals have been given a second chance at life from receiving blood cells, including bone marrow, blood and cord blood, given by living donors unrelated to their recipients.

We urge you to consider HRSA's role in strengthening the Nation's health safety net programs and ensuring that vulnerable populations receive quality health services. By supporting, planning for and adapting to change within our health care system, we can build on the successes of the past and address new gaps that may emerge in the future. We advise that you to adopt our fiscal year 2014 request of \$7.0 billion for discretionary HRSA programs to meet the public health needs and we thank you for the opportunity to submit our recommendation to the subcommittee.

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON AGING (NIA)

Senator Mikulski, Senator Cochran and members of the subcommittee, this testimony is being submitted on behalf of the Friends of the National Institute on Aging (FoNIA), a coalition of over 50 academic, patient-centered and not-for-profit organizations that conduct, fund or advocate for scientific endeavors to improve the health and quality of life for people as they age. We appreciate the opportunity to provide testimony in support of the National Institute on Aging (NIA) and to comment on the need for sustained, long-term growth in aging research. Considering the resources the Federal Government spends on the health care costs associated with age-related diseases, we feel it makes sound economic sense to increase Federal resources for aging research. Specifically, given the unique funding challenges facing the NIA, and the range of promising scientific opportunities in the field of aging research, the FoNIA recommends \$1.4 billion in fiscal year 2014 for NIA. In addition, to ensure that progress in the Nation's biomedical, social, and behavioral research continues, the Coalition also endorses the Ad Hoc Group for Medical Research in supporting \$32 billion for NIH in fiscal year 2014.

The NIA leads the national scientific effort to understand the nature of aging in order to promote the health and well-being of older adults whose numbers are projected to increase dramatically in the coming years due to increased life expectancy and the aging of the baby boom generation. According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase threefold, to 19 million. As the 65+ population increases, so will the prevalence of diseases disproportionately affecting older people—most notably, Alzheimer's disease (AD). NIA is the primary Federal agency responsible for (AD) research and receives nearly 70 percent of the NIH Alzheimer's disease research funding. Yet, we know that as many as 5 million Americans aged 65 years and older may have AD with a predicted increase to 13.2 million by 2050 (Hebert, Weuve, Scherr, et al, 2013). Last year, NIA led the AD Research Summit, which brought together officials representing Federal agencies, scientific researchers, providers, caregivers, patients and their families to develop final recommendations to the National Alzheimer's Project Act Advisory Council. NIA also supported research that identified relevant AD biomarkers through the groundbreaking Alzheimer's Disease Neuroimaging Initiative, along with a deeper understanding of the disease's pathology and clinical course. This led to the first revision of the clinical diagnostic criteria in AD in 27 years. In a recent, highly promising pilot trial, a nasal-spray form of insulin delayed memory loss and preserved cognition in people with a range of cognitive deficits. A larger-scale study to confirm and extend these results is under development. NIA is making great strides, but the resources are inadequate given the explosion of people with AD that is predicted.

NIA's current budget does not reflect the tremendous responsibility it has to meet the health research needs of a growing U.S. aging population. While the current dollars appropriated to NIA seem to have risen significantly since fiscal year 2003, when adjusted for inflation, they have decreased almost 18 percent in the last 9 years. According to the NIH Almanac, out of each dollar appropriated to NIH, only 3.6 cents goes toward supporting the work of the NIA—compared to 16.5 cents to the National Cancer Institute, 14.6 cents to the National Institute of Allergy and Infectious Diseases, 10 cents to the National Heart, Lung and Blood Institute, and 6.3 cents to the National Institute of Diabetes and Digestive and Kidney Diseases. With an infusion of much needed support in fiscal year 2014, NIA can achieve greater parity with its NIH counterparts and expand promising, recent research activities, such as:

- implementing new prevention and treatment clinical trials, research training initiatives, care interventions, and genetic research studies developed as part of the National Alzheimer's Action Plan;
- launching trans-NIH research initiatives developed by the NIH Geroscience Interest Group to reduce the burden of age-related disease;
- understanding the impact of economic concerns on older adults by examining work and retirement behavior, health and functional ability, and policies that influence individual wellbeing;
- supporting family caregivers by enhancing physician-family communication during end-of-life and critical care; and,
- increasing healthy lifespan in humans by testing and applying evidence derived from animal models.

NIA is poised to accelerate the scientific discoveries that we as a nation are counting on. With millions of Americans facing the loss of their functional abilities, their independence, and their lives to chronic diseases of aging, there is a pressing need

for robust and sustained investment in the work of the NIA. In every community in America, healthcare providers depend upon NIA-funded discoveries to help their patients and caregivers lead healthier and more independent lives. In these same communities, parents are hoping NIA-funded discoveries will ensure that their children have a brighter future, free from the diseases and conditions of aging that plague our Nation today. Chronic diseases associated with aging afflict 80 percent of the age 65+ population and account for more than 75 percent of Medicare and other Federal health expenditures. Unprecedented increases in age-related diseases as the population ages are one reason the Congressional Budget Office projects that total spending on healthcare will rise to 25 percent of the U.S. GDP by 2025—it is 17 percent of GDP today.

Recent significant findings from NIA's Division of Biology Aging that could help advance understanding of a range of chronic diseases, include the discovery of the drug rapamycin, which has been shown to extend median lifespan in a mouse model. Grantees supported by this program have also identified genetic pathways that regulate the maintenance of the stem cell microenvironment in aging tissues.

A signature project of the Behavioral and Social Science Research Division is the Health and Retirement Study (HRS), the Nation's leading source of combined data on health and financial circumstances of Americans over age 50. HRS data provide evidence about the effects of early-life exposures on later-life health, factors associated with cognitive and functional decline, and trends in retirement, savings, and other economic behaviors. The study is being replicated in 30 other countries. Last year, genetic data from approximately 13,000 individuals were posted to NIH's online database, including approximately 2.5 million genetic markers from each person. These data are available for analysis by qualified researchers and will enhance the ability to track the onset and progression of diseases and conditions affecting the elderly.

Research that can be translated quickly into effective prevention and efficient health care will reduce the burden of a "Silver Tsunami" of age-associated chronic diseases. Breakthroughs from NIA research can lead to treatments and public health interventions that could delay the onset of costly conditions such as arthritis, heart disease, stroke, diabetes, bone fractures, age-related blindness, Alzheimer's, ALS, and Parkinson's diseases. Such advances could save trillions of dollars by the middle of the current century.

We do not yet have the knowledge needed to predict, preempt, and prevent the broad spectrum of diseases and conditions associated with aging. We do not yet have sufficient knowledge about disease processes to fully understand how best to prevent, diagnose, and treat diseases and conditions of aging, nor do we have the knowledge needed about the complex relationships among biology, genetics, and behavioral and social factors related to aging. We do not yet have a sufficient pool of new investigators entering the field of aging research. Bold, visionary, and sustainable investments in the NIA will make it possible to achieve substantial and measurable gains in these areas sooner rather than later, and perhaps too late.

We recognize the tremendous fiscal challenges facing our Nation and that there are many worthy, pressing priorities to support. However, we believe a commitment to the Nation's aging population by making bold, wise investments in programs will benefit them and future generations. Investing in NIA is one of the smartest investments Congress can make.

REFERENCE

Alzheimer disease in the U.S. (2010–2050) estimated using the 1990 Census, Liesi E. Hebert, Jennifer Weuve, Paul A. Scherr, et al., *Neurology*; Published online before print February 6, 2013; WNL.0b013e31828726f5.

FRIENDS OF THE NATIONAL INSTITUTE ON AGING

Alliance for Aging Research	American Psychological Association
Alzheimer's Association	American Public Health Association
Alzheimer's Foundation of America	American Society for Bone and Mineral Research
American Academy of Dermatology	American Society for Nutritional Sciences
American Association for Geriatric Psychiatry	American Society of Consultant Pharmacists
American Chronic Pain Association	American Society of Hematology
American Federation for Aging Research	American Society on Aging
American Geriatrics Society	Arthritis Foundation
American Heart Association	
American Pain Foundation	

Association of Jewish Aging Services	National Council on the Aging
Association for Psychological Science	National Hispanic Council on Aging
Association of Population Centers	National Hospice and Palliative Care Organization
B'nai B'rith International	National Vision Rehabilitation Association
BrightFocus Foundation	Oral Health America
Brown Medical School	Parkinson's Action Network
Consortium of Social Science Associations	Population Association of America
Council on Social Work Education	Society for Neuroscience
Hospice Foundation of America	Society for Women's Health Research
IEEE-USA	Special Care Dentistry
Institute for the Advancement of Social Work Research	The Ellison Medical Foundation
National Association of Social Workers	The Endocrine Society
National Council on the Aging	The George Washington University Medical Center
National Hispanic Council on Aging	The Gerontological Society of America
International Cancer Advocacy Network (ICAN)	The North American Menopause Society
International Foundation for Anti-Cancer Drug Discovery	The Paget Foundation
International Longevity Center—USA	The Simon Foundation for Continence
Merck Institute of Aging and Health	University of Pennsylvania Institute on Aging
National Alliance for Caregiving	University of Virginia
National Association of Social Workers	USAgainstAlzheimer's

PREPARED STATEMENT OF THE FRIENDS OF THE NATIONAL INSTITUTE ON DRUG ABUSE

Mr. Chairman and members of the subcommittee, thank you for the opportunity to submit testimony to the subcommittee in support of the National Institute on Drug Abuse. The Friends of the National Institute on Drug Abuse is a coalition of over 150 scientific and professional societies, patient groups, and other organizations committed to, preventing and treating substance use disorders as well as understanding their causes through the research agenda of the National Institute on Drug Abuse (NIDA). We are pleased to provide testimony in support of the work carried out by scholars around the country whose work is supported by NIDA.

Recognizing that so many health research issues are inter-related, Friends of the National Institute on Drug Abuse (NIDA) requests that the subcommittee provide at least \$32 billion for the National Institutes of Health (NIH). Because of the critical importance of drug abuse research for the health and economy of our Nation, we also request that you provide a proportionate increase for the National Institute on Drug Abuse in your Fiscal 2014 Labor, Health and Human Services, Education and Related Agencies Appropriations bill.

Drug abuse is costly to Americans; it ruins lives, while tearing at the fabric of our society and taking a huge financial toll on our resources. Beyond the unacceptably high rates of morbidity and mortality, drug abuse is often implicated in family disintegration, loss of employment, failure in school, domestic violence, child abuse, and other crimes. Placing dollar figures on the problem; smoking, alcohol and illegal drug use results in an exorbitant economic cost on our Nation, estimated at over \$600 billion annually. We know that many of these problems can be prevented entirely, and that the longer we can delay initiation of any use, the more successfully we mitigate future morbidity, mortality and economic burdens.

Over the past three decades, NIDA-supported research has revolutionized our understanding of addiction as a chronic, often-relapsing brain disease—this new knowledge has helped to correctly situate drug addiction as a serious public health issue that demands strategic solutions. By supporting research that reveals how drugs affect the brain and behavior and how multiple factors influence drug abuse and its consequences, scholars supported by NIDA continue to advance effective strategies to prevent people from ever using drugs and to treat them when they cannot stop.

NIDA supports a comprehensive research portfolio that spans the continuum of basic neuroscience, behavior and genetics research through medications development and applied health services research and epidemiology. While supporting research on the positive effects of evidence-based prevention and treatment approaches, NIDA also recognizes the need to keep pace with emerging problems. We have seen encouraging trends—significant declines in a wide array of youth drug

use—over the past several years that we think are due, at least in part, to NIDA's public education and awareness efforts. However, areas of significant concern, such as prescription drug abuse, remain and we support NIDA in its efforts to find successful approaches to these difficult problems.

The Nation's previous investment in scientific research to further understand the effects of abused drugs on the body has increased our ability to prevent and treat addiction. As with other diseases, much more needs to be done to improve prevention and treatment of these dangerous and costly diseases. Our knowledge of how drugs work in the brain, their health consequences, how to treat people already addicted, and what constitutes effective prevention strategies has increased dramatically due to support of this research. However, since the number of individuals continuing to be affected is still rising, we need to continue the work until this disease is both prevented and eliminated from society.

We understand that the fiscal year 2014 budget cycle will involve setting priorities and accepting compromise, however, in the current climate we believe a focus on substance abuse and addiction, which according to the World Health Organization account for nearly 20 percent of disabilities among 15–44 year olds, deserves to be prioritized accordingly. We look forward to working with you to make this a reality. Thank you for your support for the National Institute on Drug Abuse.

PREPARED STATEMENT OF THE FSH SOCIETY, INC.

Honorable Chairwoman Mikulski and Ranking Member Harkin, thank you for the opportunity to submit this testimony. I am Daniel Paul Perez, of Bedford, Massachusetts, President and CEO of the FSH Society, Inc. and an individual who has lived with facioscapulohumeral muscular dystrophy (FSHD) for 51 years. For hundreds of thousands of men, women, and children worldwide the major consequence of inheriting this form of muscular dystrophy is a lifelong progressive loss of all skeletal muscles. FSHD is a crippling and life shortening disease. No one is immune. It is both genetically and spontaneously transmitted to children. It can affect multiple generations and entire family constellations.

The National Institutes of Health (NIH) is the principal source of funding of research on Facioscapulohumeral Muscular Dystrophy (FSHD) currently at the \$6 million level. Over many years, this Committee has supported the incremental growth in funding for FSHD research. I am pleased to report that this modest investment has produced huge scientific returns.

1. CONGRESS HAS MADE A MAJOR DIFFERENCE IN MUSCULAR DYSTROPHY

I have testified many times before Congress. When I first testified, we did not know the mechanism of this disease. Now we do. When I first testified, we assumed that FSHD was a rare form of muscular dystrophy. Now we understand it to be one of the most prevalent forms of muscular dystrophy. Congress is responsible for this success, through its sustaining support of the National Institutes of Health (NIH), and the enactment of the Muscular Dystrophy CARE Act. I am testifying in order to document this success and call on Congress to continue the momentum of discovery you have set in motion.

Congress enacted The Muscular Dystrophy Community Assistance, Research and Education Amendments of 2001 (the MD-CARE Act, Public Law 107–84) on December 18, 2001. It was reauthorized in 2008 and new efforts are underway to reauthorize the MD-CARE Act as it will expire in 2013. We are hopeful that this reauthorization bill will receive the same overwhelming bi-partisan support enjoyed in earlier enactments.

2. QUANTUM LEAPS IN OUR UNDERSTANDING OF FSHD HAVE OCCURRED IN PAST 3 YEARS

The past 3 years have seen remarkable contributions made by researchers funded by NIH.

—On August 19, 2010, American and Dutch researchers published a paper which dramatically expanded our understanding of the mechanism of FSHD.¹ A front page story in the New York Times quoted the NIH Director Dr. Francis Collins

¹Lemmers, RJ, et al, A Unifying Genetic Model for Facioscapulohumeral Muscular Dystrophy *Science* 24 September 2010: Vol. 329 no. 5999 pp. 1650–1653.

saying, “If we were thinking of a collection of the genome’s greatest hits, this would go on the list.”²

- Two months later, another paper was published that made a second critical advance in determining the cause of FSHD.³ The research shows that FSHD is caused by the inefficient suppression of a gene that may be normally expressed only in early development.
- On January 17, 2012, an international team of researchers based out of Seattle discovered a gene called DUX4 required to develop chromosome 4-linked FSHD.⁴
- Six months later, another high profile paper produced by the NIH funded University of Massachusetts Senator Paul D. Wellstone Cooperative Research Center for FSHD, used sufficiently “powered” large collections of genetically matched FSHD cell lines generated by the NIH center that are both unique in scope and shared with all researchers worldwide, to improve on the Seattle group’s finding by postulating that DUX4-fl expression is necessary but not sufficient by itself for FSHD muscle pathology.⁵ This work was also supported by a NIH cooperative research center grant mandated by MD CARE Act.
- On July 13, 2012, a team of international researchers from the, United States, Netherlands and France identified mutations in a gene causing 80 percent of another form of FSHD. This paper furthers our understanding of the molecular pathophysiology of FSHD. This work too was supported in part by a program project grant from NIH.⁶
- On April 4, 2013, an international team published a mouse model that appears more promising than previous models of FSHD. The result of a decade’s worth of work, during which scientific understanding of FSHD exploded. “We hope that in the near future these mouse models will serve an important purpose in drug development programs for FSHD,” remarked senior author Silvere van der Maarel of Leiden University in the Netherlands. The herculean project was initiated in 2003, by the FSH Society’s Marjorie Bronfman Fellowship grant. The patient-driven charity was seeking a definitive mouse model based on a genetic unit called D4Z4. Normally, people have ten or more of these units, repeated one after the other near the tip of chromosome 4. The majority of FSHD patients, in contrast, have fewer than ten D4Z4 units. The newly published mouse model contains 2.5 copies of the D4Z4 unit, a truncated number comparable to that seen in human FSHD patients. The D4Z4 unit contains the gene called DUX4, which is toxic to muscle cells.⁷ This work was also supported by NIH grants.

I am proud to say that many of these researchers have started their efforts in FSHD with seed funding from the FSH Society and have received continued support from the FSH Society, the National Institutes of Health, and the Muscular Dystrophy Association and other partners. This shows the power of the collaboration among funders, patient groups and researchers to advance the search for cures and treatments.

3. REMARKABLE PROGRESS IN FSHD RESEARCH AND THE NEED TO KEEP MOVING FORWARD

Given the recent developments, there is a need to ramp up the preclinical enterprise and build/organize infrastructure needed to conduct clinical trials. Our immediate priorities should be to confirm the new hypotheses and targets. We need to

²Kolata, G., Reanimated ‘Junk’ DNA Is Found to Cause Disease. *New York Times*, Science. Published online: August 19, 2010 <http://www.nytimes.com/2010/08/20/science/20gene.html>.

³Snider, L., Geng, L.N., Lemmers, R.J., Kyba, M., Ware, C.B., Nelson, A.M., Tawil, R., Filippova, G.N., van der Maarel, S.M., Tapscott, S.J., and Miller, D.G. (2010). Facioscapulohumeral dystrophy: incomplete suppression of a retrotransposed gene. *PLoS Genet.* 6, e1001181.

⁴Geng et al., DUX4 Activates Germline Genes, Retroelements, and Immune Mediators: Implications for Facioscapulohumeral Dystrophy, *Developmental Cell* (2012), doi:10.1016/j.devcel.2011.11.013.

⁵Jones TI, et al, Facioscapulohumeral muscular dystrophy family studies of DUX4 expression: evidence for disease modifiers and a quantitative model of pathogenesis. *Hum Mol Genet.* 2012 Oct 15;21(20):4419–30. Epub 2012 Jul 13.

⁶Lemmers, R.J, et al, Digenic inheritance of an SMCHD1 mutation and an FSHD-permissive D4Z4 allele causes facioscapulohumeral muscular dystrophy type 2. *Nat Genet.* 2012 Dec;44(12):1370–4. doi: 10.1038/ng.2454. Epub 2012 Nov 11.

⁷Krom YD, Thijssen PE, Young JM, den Hamer B, Balog J, et al. (2013) Intrinsic Epigenetic Regulation of the D4Z4 Macrosatellite Repeat in a Transgenic Mouse Model for FSHD. *PLoS Genet* 9(4): e1003415. doi:10.1371/journal.pgen.1003415.

be prepared for this new era in the science of FSHD, by accelerating efforts in the following five areas:⁸

1. *Genetics/epigenetics.*—There is general acceptance that transcriptional deregulation of D4Z4 is central to FSHD1 and FSHD2. The FSHD2 gene SMCHD1 explains approximately 80 percent of FSHD2. There is a need for better understanding of the factors that modulate DUX4 activity and disease penetrance.

2. *FSHD molecular networks.*—D4Z4 chromatin relaxation on FSHD-permissive chromosome-4 haplotypes leads to activation of downstream molecular networks. In addition to considering DUX4 as the “target” and downstream targets, the upstream processes and targets—triggering of activation—are equally important. Hence, understanding what DUX4lf does as a target and targets up- and down-stream of it are priorities. Detailed studies on these processes are crucial for insight in the molecular mechanisms of FSHD pathogenesis and may contribute to explaining the large intra- and interfamilial clinical variability. Importantly such work may lead to intervention (possibly also prevention) targets. Additional FSHD genes and modifiers are still likely to exist. Apart from chromatin modifiers, these include, but are not limited to, CAPN3 and the FAT1 gene that was recently suggested to be involved in FSHD.

3. *Clinical trial readiness.*—It is now broadly accepted that deregulation of the expression of D4Z4/DUX4 is at the heart of FSHD1 and FSHD2. This finding opens perspectives for intervention along different avenues. Intervention trials are envisaged within the next several years. The FSHD field needs to be prepared for this crucial step. There is an increasing need to improve the translational process. This includes, but is not limited to, the need for consensus on data capture and storage, overcoming national and international barriers, definition of natural history, identification of (meaningful) and sensitive outcome measures, biomarkers, and meaningful functional measures. There is a need to work more closely with FDA to help define acceptable measures for trials.

4. *Model systems.*—There was already a good set of cellular and models, based on different pathogenic (candidate gene) hypotheses. This was further expanded during the last year. The phenotypes are very diverse and often difficult to compare with the human FSHD phenotype. Many basic questions remain unanswered and clearly need to be answered for further translational studies: when and where is DUX4 expressed in skeletal muscle and what regulates DUX4 activity. It was recognized that there still exists a gap in our knowledge linking the basic genetic and molecular findings with the observed muscle pathology. The University of Massachusetts NIH Sen. Wellstone center and the University of Rochester continue to generate human cellular resources. These resources continuously deserve attention and need to be replenished. Recent progress in ES-cell technology, including iPS lines, allows for inter-group distribution and dedicated molecular (epi)genetic studies.

5. *Sharing.*—Timely sharing of information and resources remains a critical contributor to the progress in the field. Sharing of resources other information remains a priority (e.g. protocols, guide to FSHD muscle pathology, etc.).

We would be pleased to provide the Committee with detailed information on each of these areas. The pace of discovery and numbers of experts in the field of biological science and clinical medicine working on FSHD are rapidly expanding. Many leading experts are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes and new ways of treating human disease.

4. NIH FUNDING FOR MUSCULAR DYSTROPHY

Mr. Chairman, these major advances in scientific understanding and epidemiological surveillance are not free. They come at a cost. Since Congress passed the MD CARE Act, research funding at NIH for muscular dystrophy has increased 4-fold. While FSHD research funding has increased 12-fold during this period, the level of funding is still exceedingly modest.

⁸ 2012 FSH Society FSHD International Research Consortium, held November 6, 2012 co-sponsored by DHHS NIH NICHD Boston Biomedical Research Institute Senator Paul D. Wellstone MD CRC for FSHD. To read the expanded summary and recommendations of the group see: <http://www.fshsociety.org/pages/sciConsortium.html>.

FSHD RESEARCH DOLLARS & FSHD AS A PERCENTAGE OF TOTAL NIH MUSCULAR DYSTROPHY
FUNDING

	Fiscal Year—												
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012e
All MD (\$ millions)	12.6	21	27.6	39.1	38.7	39.5	39.9	47.2	56	83	86	75	75
FSHD (\$ millions)	0.4	0.5	1.3	1.5	2.2	2.0	1.7	3	3	5	6	6	6
FSHD (percent total MD)	3	2	5	4	6	5	4	5	5	6	7	8	8

Sources: NIH/OD Budget Office & NIH OCPL & NIH RCDC RePORT
(e = estimate; as fiscal year 2012 actuals not available on-line as of March 12, 2013)

Despite the great success of the past two and a half years in the science of FSHD brought about by Congress we are concerned that the budget cuts required by the sequester are coming at a time when many of the FSHD research projects are ending. It is likely that new research projects will not be funded or existing programs will not be renewed. This is a perfect storm that could have devastating effects on FSHD research efforts. I served on the Federal advisory committee MDCC for 9 years until 2011. We have conveyed to the Executive Secretary of the MDCC our grave concern that the current portfolio of research on FSHD has a disproportionate number of FSHD grants near the end or in the last year of their grant cycles. While most are competitively renewable this occurrence could not have happened at a worst time with sequestration making meat axe cuts across all Federal agencies.

We request for fiscal year 2014, a doubling of the facioscapulohumeral muscular dystrophy (FSHD) research budget to \$12 million dollars. This will allow an expansion of the U.S. DHHS NIH Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, an increase in research awards, expansion of post-doctoral and clinical training fellowships, and a dedicated center to design and conduct clinical trials on FSHD.

We are aware of the great pressures on the Federal budget, but cutting the NIH budget and research funding for FSHD at this time would be the wrong decision. We have come so far with such modest funding. This is not the time to lessen our endeavor. This is the time to fully and expeditiously exploit the advances for which the American taxpayer has paid.

Thank you for this opportunity to testify before your committee.

PREPARED STATEMENT OF THE GIRL SCOUTS OF THE USA

As the preeminent leadership development organization for girls, Girl Scouts of the USA (Girl Scouts) serves over two million girls each year, ages 5 to 17, from every corner of the United States and its territories, with value placed on diversity and inclusiveness. We also serve nearly 17,000 American girls living outside of the United States in over 90 countries. Through our 112 councils, USA Girl Scouts Overseas, and more than 800,000 dedicated volunteers, we continue to deliver the Girl Scout Leadership Experience (GSLE)—the world's best and most comprehensive program for girls' leadership development.

BUILDING GIRLS' LEADERSHIP

Girl Scout experiences through GSLE are, as much as possible, girl-led and encourage hands-on and cooperative learning. The GSLE framework specifies 15 outcomes—behaviors, attitudes, skills, and values—that develop girls of courage, confidence, and character. We provide significant financial assistance to girls who cannot afford to join the Girl Scouts. In many communities, Girl Scouts is the single most visible and viable positive choice for these girls.

Research shows that girl-only settings not only provide a sense of belonging, but are also more effective environments for personal development, learning new skills, and building self-confidence. In emotionally and physically safe environments like those provided by Girl Scouts, girls partner with positive role models in a range of activities not limited by gender stereotypes. Girl Scout programs also emphasize partnerships, public education campaigns, mentorship programs, career exploration, traditional badges, and innovative programming. By combining our girl-only learning environment, our unique national program, our unparalleled delivery infrastructure, and our proven expertise working with partners, we offer powerful learning experiences for girls across all sectors, including girls in traditionally underserved and underrepresented communities. And in so doing, we are preparing a generation of girls to take leadership roles in business, society, and our collective future.

Women today are well educated but still underrepresented in high-paying and leadership positions. They face many societal barriers to leading and achieving success in fields ranging from technology and science to business and industry. With this in mind, we need a bold policy shift so that girls are able to start building the skills they need so that they are better positioned to achieve their full leadership potential as women. Girl Scouts is eager to work with policymakers to create opportunities and environments that foster girls' leadership development.

PENSION RELIEF

Under Department of Labor, General Provisions, Girl Scouts respectfully requests the insertion of the following language as our highest priority request:

Sec. ____ . ELECTION NOT TO BE TREATED AS AN ELIGIBLE CHARITY PLAN. A plan sponsor of an eligible charity plan (as defined in subsection (d) of section 104 of the Pension Protection Act of 2006) may elect, effective for the first plan year beginning after December 31, 2013, to have section 104 of such Act not apply to such plan. In the case of such an election, solely for plan years beginning after December 31, 2013, section 430(c) of the Internal Revenue Code of 1986 and section 303(c) of the Employee Retirement Income Security Act of 1974 shall apply as if such sections had applied to the first two plan years beginning after December 31, 2009, and as if the plan sponsor had elected to apply section 430(c)(2)(D)(iii) of such Code and section 303(c)(2)(D)(iii) of such Act with respect to those two plan years.

The proposed language, which would only affect eligible charities and thus should not have an associated cost, would modify the rule established by section 202(b) of the Preservation of Access to Care for Medicare Beneficiaries and Pension Relief Act of 2010, Public Law 111–192. The effect of the proposed language is similar in effect to section 2 of H.R. 4915, as passed by the Senate in December of 2010, which also allowed a plan sponsor of an eligible charity plan not to have section 104 of the Pension Protection Act of 2006 apply.

Girl Scouts of the USA, on behalf of the millions of girls we serve, respectfully requests this technical fix. The language simply says that, as of 2014, we, and all similarly structured charities, be permitted to elect in to the Pension Protection Act funding rules, which are the Federal pension rules applicable to corporate America.

In addition to our request pertaining to pension relief, the following are the key policy priority areas where we can offer research and programmatic success stories:

STEM EDUCATION

As the preeminent organization for girls and a leader on informal STEM education, Girl Scouts is committed to ensuring that every girl has the opportunity to explore and build an interest in science, technology, engineering, and mathematics. The strength of our Nation depends on increasing girls' involvement in STEM so that they can develop critical thinking, problem solving, and collaboration skills that will serve be important throughout their lives.

In 2012, the Girl Scout Research Institute (GSRI) released Generation STEM: What Girls Say about Science, Technology, Engineering, and Math, which found that girls are interested in STEM subjects and aspire to STEM careers, but need further exposure and education about what STEM careers can offer and how STEM can help girls make a difference in the world.

Among some of Generation STEM's other findings:

- 74 percent of teen girls are interested in STEM fields and STEM subjects. Girls like the process of learning, asking questions, and problem solving.
- Girls who are interested in STEM are significantly better students and have higher confidence in their abilities and higher academic goals.
- But while 81 percent say they are interested in pursuing a STEM career, only 13 percent say it's their first choice. About half of all girls feel that STEM isn't a typical career path for girls. Fifty-seven percent of girls say that if they went into a STEM career, they'd have to work harder than a man just to be taken seriously.
- African American and Hispanic girls have high interest in STEM, high confidence, and a strong work ethic, but they also say they have fewer supports and less STEM exposure than Caucasian girls.

As Congress considers consolidations and a redesign of existing Federal STEM programs, we urge you to focus more on engaging and motivating girls in STEM, in particular younger girls and girls in underrepresented communities. Strategies include introducing girls to diverse role models and mentors; promoting proven techniques for engaging girls in STEM, such as single-gender learning; and hands-on and experiential learning opportunities in after-school or out-of-school environments.

FINANCIAL LITERACY

The world's current economic challenges have made financial literacy matter now more than ever. Girl Scouts offers a financial literacy program at every grade level, K–12. Through our Girl Scout financial education programming, girls learn to handle money and the basics of budgeting, banking, saving, using credit, planning for retirement, and even practicing philanthropy.

Additionally, the Girl Scout Cookie Program is often girls' first foray into business planning and entrepreneurship. The \$790-million program is the largest girl-led business in the world.

While lack of financial literacy is a growing concern, relatively little research has been conducted on how girls think about and experience money and finances. To address this gap, the Girl Scout Research Institute recently conducted a study, *Having It All: Girls and Financial Literacy*, with girls and their parents. It found that girls need and want financial literacy skills to help them achieve their dreams, with 90 percent saying it is important for them to learn how to manage money. However, just 12 percent of girls surveyed feel "very confident" about making financial decisions.

To be successful and sustainable, financial education must begin early, be relevant, and continue throughout elementary and secondary education. And although 93 percent of the public believes all high school students should be required to take a class in financial education, only four States have made a semester-long course in financial literacy a graduation requirement.¹ In addition to providing teachers with training and materials, we believe policy makers should increase support for critical after-school and community-based programs so that girls have the opportunity to learn money-management skills and have real-world financial literacy experiences that will serve them throughout their lives.

HEALTHY LIVING—BULLYING AND RELATIONAL AGGRESSION

As exemplified through our program experience and research, Girl Scouts understands the complex issue of healthy living and what motivates youth—especially girls—to adopt healthy lifestyles. Improving youths' physical health and emotional well-being are not mutually exclusive. Youth, especially girls, experience them in an interrelated fashion. Girls place the same or even greater emphasis on social and emotional health as physical health.

The Girl Scout Research Institute's original research report, *Feeling Safe: What Girls Say*, found that nearly half (46 percent) of girls define safety as not having their feelings hurt, and approximately one-third of all girls worry about being teased, bullied, threatened, or having their feelings hurt when spending time with peers, participating in groups, and trying new things. Another GSRI report, *The New Normal? What Girls Say About Healthy Living*, tells us that a girl's relationships with her peers are critical components of her health and safety.

Our BFF (Be a Friend First) curriculum is focused on middle-school girls and designed to easily integrate into existing health or character education classes. It can even serve as an after-school program in the community.

The Department of Education has proposed a safe schools initiative that includes a positive school climate focus, and Girl Scouts supports this kind of effort, which embraces a holistic definition of health that addresses both the physical health and emotional wellness of youth. National youth-serving organizations such as Girl Scouts should be seen as vital partners for schools in developing relevant solutions, such as policies and programs that address relational aggression and building healthy relationships.

CLOSING

We look forward to being a partner with Congress as you make difficult funding decisions in the areas of supporting healthy living, improving the financial education of our youth, and building a pipeline of girls and underrepresented minorities in STEM careers. Thank you, and please consider us a resource in these areas.

PREPARED STATEMENT OF THE GLOBAL HEALTH TECHNOLOGIES COALITION

Chairman Harkin, Ranking Member Moran, and Members of the Committee, thank you for the opportunity to provide testimony on the fiscal year 2014 appropriations funding for the National Institutes of Health (NIH) and the Centers for

¹*Back to School Survey Shows Americans Want Personal Finance Taught in the Classroom*, Visa, July 20, 2010.

Disease Control and Prevention (CDC). We appreciate your leadership in promoting the importance of international development, in particular global health. We hope that your support will continue. I am submitting this testimony on behalf of the Global Health Technologies Coalition (GHTC), a group of over 25 nonprofit organizations working together to promote the advancement of research and development (R&D) of new global health innovations—including new vaccines, drugs, diagnostics, microbicides, and other tools—to combat global health diseases. The GHTC's members strongly believe that to meet the global health needs of tomorrow, it is critical to invest in research today so that the most effective health solutions are available when we need them. My testimony reflects the needs expressed by our member organizations which work with a wide variety of partners to develop new and more effective life-saving technologies for the world's most pressing health issues. We strongly urge the Committee to continue its established support for global health R&D by (1) sustaining and supporting the U.S. investment in global health research and product development by providing \$32 billion for NIH, and providing robust funding for CDC, with \$362.9 million for the CDC Center for Global Health, (2) requiring leaders at the National Institutes for Health, the Centers for Disease Control and Prevention, the Food and Drug Administration and the Secretariat of the U.S. Department of Health and Human Services to join leaders of other U.S. agencies to develop a five-year cross-Government strategy for global health research and product development, and to ensure that global health R&D is robust, efficient, coordinated, and streamlined, (3) instructing the NIH and CDC, in collaboration with other agencies involved in global health, to continue their commitment to global health in their R&D programs, and to document coordination efforts between agencies for the use of Congress and the public, and (3) to request that the newly-formed National Center for Advancing Translational Sciences (NCATS) expand its clinical trials mandate to include all stages of research.

Critical need for new global health tools

Our Nation's investments have made historic strides in promoting better health around the world: nearly six million people living with HIV/AIDS now have access to life-saving medicines; new, cost-effective tools help us diagnose diseases quicker and more efficiently than ever before; and innovative new vaccines are making significant dents in childhood mortality. While we must increase access to these and other proven, existing health tools to tackle global health problems, it is just as critical that we continue to invest in developing the next generation of tools to stamp out disease and address current and emerging threats. For instance, newer, more robust, and easier to use antiretroviral drugs (ARV), particularly for infants and young children, are needed to treat and prevent HIV, and even an AIDS vaccine that is 50 percent effective has the potential to prevent one million HIV infections every year. Drug-resistant tuberculosis (TB) is on the rise globally, including in the United States, however the only vaccine on the market is insufficient at 90 years old, and most therapies are more than 50 years old, extremely toxic, and too expensive. New tools are also urgently needed to address fatal neglected tropical diseases (NTDs) such as sleeping sickness, for which diagnostic tools are inadequate and the few drugs available are toxic or difficult to use. There are many very promising technology candidates in the R&D pipeline to address these and other health issues; however, these tools will never be available if the support needed to continue R&D is not supported and sustained.

Research and U.S. global health efforts

The United States is at the forefront of innovation in global health technologies. For example, in November 2010, the NIH announced the results of the iPrEx clinical trial, a large, multi-country research study examining pre-exposure prophylaxis (PrEP). The study found that a daily dose of two anti-retroviral drugs could provide an average of 44 percent additional protection to high-risk populations who also received a comprehensive package of HIV prevention services. Additional studies supported by the CDC and the University of Washington confirmed that a daily oral dose of ARV drugs used to treat HIV infection can reduce the risk of HIV acquisition among uninfected individuals by between 63 and 73 percent.

The NIH is the largest funder of global health research in the U.S. Government, and the agency continues to demonstrate growing interest in global health issues, particularly in the area of translational research. NIH Director Francis Collins has made global health one of his top five priorities for the future of the NIH, and our coalition members have been pleased to see this implemented via the launch of a new Center for Global Health Studies at the Fogarty International Center, new initiatives on global health at the National Cancer Institute, ongoing exceptional work of the National Institute for Allergy and Infectious Diseases (NIAID), and the cre-

ation of the new National Center for Advancing Translational Sciences (NCATS). Additionally, the Model Non-Profit License Agreement for NTDs, HIV, TB, and Malaria Technologies was created for nonprofit institutions and PDPs with a demonstrated commitment to neglected diseases to apply for the use of patented inventions and non-patented biological materials from the NIH and the FDA intramural laboratories. Finally, NCATS recently began a pilot partnership between NCATS and private industry aimed at finding new cures and treatments using a library of compounds that already exist. Each of these efforts built on the historic work carried out by the agency which contributes to improved health around the world.

With operations in more than 54 countries, the CDC is engaged in many global health research efforts. The work of CDC scientists has led to major advances against devastating diseases. Although the CDC is known for its expertise and participation in HIV, TB, and malaria programs, it also operates several activities for neglected diseases in its National Center for Zoonotic, Vector-Borne, and Enteric Diseases. The CDC's Center for Global Health employs 1,100 staff members, and has people on the ground in 55 countries.

Leveraging the private sector for innovation

The NIH, CDC, and other U.S. agencies involved in global health R&D regularly collaborate with the private sector in developing, manufacturing, and introducing important technologies such as those described above through public-private partnerships, including product development partnerships. These partnerships leverage public-sector expertise in developing new tools, partnering with academia, large pharmaceutical companies, the biotechnology industry, and governments in developing countries to drive greater development of products for neglected diseases in which private industries have not historically invested. This unique model has generated sixteen new global health products and has enormous potential for continued success if robustly supported. NIH Director Francis Collins has stated that such partnership is key to the development of therapies and health tools based on NIH-funded research.

Innovation as a smart economic choice

Global health R&D brings life-saving tools to those who need them most, however the benefits of these efforts bring are much broader than preventing and treating disease. Global health R&D is also a smart economic investment in the United States, where it drives job creation, spurs business activity, and benefits academic institutions. Biomedical research, including global health, is a \$100 billion enterprise in the United States. Sixty-four cents out of every U.S. dollar invested in global health R&D goes directly to U.S.-based researchers. In a time of global financial uncertainty, it is important that the United States support industries, such as global health R&D, which build the economy at home and abroad.

An investment made today can help save significant money in the future. The recently released meningitis A vaccine MenAfriVac is on course to save nearly \$600 million in health care costs over the next decade. In addition, new therapies to treat drug-resistant tuberculosis have the potential to reduce the price of tuberculosis treatment by 90 percent and cut health system costs significantly. The United States has made smart investments in research in the past that have resulted in lifesaving breakthroughs for global health diseases, as well as important advances in diseases endemic to the United States. We must now build on those investments to turn those discoveries into new vaccines, drugs, tests, and other tools.

Recommendations

In this time of fiscal constraint, support for global health research that improves the lives of people around the world—while at the same time creating jobs and spurring economic growth at home—should unquestionably be one of the Nation's highest priorities. In keeping with this value, the GHTC respectfully requests that the Committee do the following:

- Sustain and support U.S. investment in global health research and product development by fully funding NIH, CDC, and FDA to carry out their work.
- Require leaders at the National Institutes for Health, the Centers for Disease Control and Prevention, the Food and Drug Administration and the Secretariat of the U.S. Department of Health and Human Services to join leaders of other U.S. agencies to develop a five-year cross-Government strategy for global health research and product development, and to ensure that global health R&D is robust, efficient, coordinated, and streamlined.
- Instruct the NIH and CDC, in collaboration with other agencies involved in global health, to continue their commitment to global health within their R&D programs, and to request that the newly-formed National Center for Advancing

Translational Sciences (NCATS) expand its clinical trials mandate to include all stages of research.

- Instruct the FDA to continue to elevate global health in its mandate by creating an office of neglected diseases, building stronger partnerships with global regulatory stakeholders, ensuring that it can review health products for all neglected diseases, taking steps to increase transparency by reporting to Congress on its neglected disease activities, and strengthening its internal capacity on global health.

As a leader in science and technology, the United States has the ability to capitalize upon our strengths to help reduce illness and death and ultimately eliminate disabling and fatal diseases for people worldwide, contributing to a healthier world and a more stable global economy. Sustained investments in global health research to develop new drugs, vaccines, tests, and other health tools—combined with better access to existing methods to prevent and treat disease—present the United States with an opportunity to dramatically alter the course of global health while building political and economic security across the globe.

On behalf of the members of the GHTC, I would like to extend my gratitude to the Committee for the opportunity to submit written testimony for the record.

PREPARED STATEMENT OF THE GUILLAIN-BARRÉ SYNDROME (GBS)/CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY (CIDP) FOUNDATION, INTERNATIONAL

Fiscal Year 2014 Appropriations Recommendations:

- For the National Institutes of Health, provide \$32 billion in fiscal year 2014, with proportional increases to the National Institute of Neurological Disorders and Stroke, the National Center for Advancing Translational Sciences, the National Institutes of Allergy and Infectious Disease and the Office of Rare Disease Research.
- The Committee recommendation for the Centers for Disease Control and Prevention to improve health outcomes for GBS and CIDP patients by promoting enhanced awareness and recognition activities in partnership with stakeholders.
- The Committee's commendation of National Institute of Neurological Disorders and Stroke research portfolio focused on disorders of the nervous system and encouragement to pursue expanded research focused on inflammatory disorders impacting the peripheral nervous system such as Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, and related conditions.
- The Committee's recommendation that the Office of Rare Diseases Research initiate research activities in peripheral nervous system disorders and express support for the National Center for Advancing Translational Sciences to pursue a GBS indication for current, off-label treatment options.

Chairman Harkin, Ranking Member Moran and members of the subcommittee, thank you for providing me with the opportunity to submit written testimony to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee on behalf of the Guillain-Barré Syndrome (GBS)/Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Foundation, International.

As a non-profit, 501(c)(3) organization, the GBS/CIDP Foundation, International advocates for research into prevention, access to affordable treatments and high quality patient care. Inspired by his experience with GBS, Bob and Estelle Benson founded the GBS/CIDP Foundation, International. Starting as a small support group for patients with GBS in 1980, the first support group meeting consisted of eight people in the Benson's dining room.

Over the past thirty years, the Foundation has expanded to over 30,000 members in 33 countries, offering support and assistance to ensure that patients with GBS, CIDP and associated disease variants are provided with proper diagnosis, treatment and support. In line with the founding principles of the Bensons, the mission of the Foundation remains to improve the quality of life for individuals and families worldwide affected by GBS, CIDP and variants by:

- Providing a network for all patients, their caregivers and families so that GBS or CIDP patients can depend on the Foundation for support, and reliable up-to-date information.
- Providing public and professional educational programs worldwide designed to heighten awareness and improve the understanding and treatment of GBS, CIDP and variants.
- Expanding the Foundation's role in sponsoring research and engaging in patient advocacy.

Guillain-Barré Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy:

GBS and CIDP are inflammatory, autoimmune disorders which affect the Peripheral Nervous System and the myelin insulation surrounding the sensory, motor or autonomic nerves. Patients with Guillain-Barré Syndrome experience a sudden onset of muscle weakness or paralysis over a few days, which presents through decreased reflexes in the arms and legs, low blood pressure and in severe cases, trouble breathing or swallowing. While the cause is unknown, nearly half of cases occur after the patient experiences a viral or bacterial infection. Given the sudden and unexpected onset of GBS, patients require swift and costly treatments with hospitalization. Patients undergo plasma exchange (PE) and physician administered intravenous immune globulins (IVIg), which lessen the severity of the acute phase and accelerate patient recovery. An estimated three thousand to six thousand Americans develop GBS each year.

Chronic Inflammatory Demyelinating Polyneuropathy is the chronic form of GBS and patients with this disease experience a gradual onset which causes weakness and often a loss of reflexes. The associated disease variants describe the development of the disease which include “progressive,” developing a several year development, “recurrent,” consisting of multiple active episodes or “monophasic”, occurring in a single episode. The management of the disease requires systematic treatments with IVIg to ensure the best patient prognosis. Without proper diagnosis and treatment, the disease can progress and leave patients disabled. CIDP is extremely rare and occurs in one out of every 1.5 to 3 million Americans.

For both GBS and CIDP, costly biologic treatments are necessary and the only medical option for the management and treatment of these chronic and life threatening conditions. Some private health insurance companies which offer prescription drug coverage, have created a “specialty” or fourth tiered payment plan for high cost treatments like IVIg. Unlike other out of pocket requirements for traditional drug co-pays, which require patients to pay \$10–\$50, patients receiving drugs on this “specialty” tier are required to pay co-insurance for the treatment, sometimes up to 25–33 percent. For IVIg, this could over \$2,500 for a single treatment.

The high costs of these “specialty” tiers place a large financial burden on GBS and CIDP patients and their families, restrict patient access to medically necessary treatments and at times force patients to go without vital, prescription drugs. The promise of federally supported medical advancements at the National Institutes of Health, into more effective treatments and lower cost treatments and hopefully one day a cure, are important to the thousands of patients impacted by these diseases each year.

Federal Investment at NIH and CDC:

The medical community has provided countless examples of the impact biomedical research has had on devastating and once terminal illnesses. Simple and small NIH grants from unknown, unestablished medical researchers have led to groundbreaking discoveries providing effective preventions and interventions, life-saving treatments and for some diseases, a cure. We cannot guarantee nor expect that if left to the private medical research and drug development sectors, these revolutionary developments would be made. Some disease like GBS, CIDP and the associated disease variants do not lend themselves to quick profit or a patient base large enough to bring about private investment. Some discoveries take the lifetime commitment of dedicated researchers that are not aimed at profits, but at people. Not aimed at fame, but of relieving human suffering.

It's not only the reason why the National Institutes of Health was established, but also why the Federal investment in medical research is so highly respected and supported by the American public. The American people support the promise of what NIH discoveries can accomplish and the impact it could have on a mother or father with Alzheimer's disease, wife or husband struck by GBS or child with cancer. And they are proud to lead the world in medical innovation and the investment it brings about. But, as the funding our Nation provides for medical research fails to keep pace with opportunity, this leadership role could be slipping through our grasp.

Reversing sequestration and the corresponding NIH cuts is imperative in our goal of maintaining the Nation's status as the leader of groundbreaking biomedical health discoveries. The GBS/CIDP Foundation supports a \$32 billion request for fiscal year 2014 for the National Institutes of Health, with proportional increases to the National Institute of Neurological Disorders and Stroke (NINDS), the National Center for Advancing Translational Sciences (NCATS), the National Institutes of Allergy and Infectious Disease and the Office of Rare Disease Research (ORDR). This increase will allow for the possibility of an expanded research portfolio focused on inflammatory disorders of the nervous system at NINDS, ORDR to initiate research

activities in peripheral nervous system disorders, and for NCATS to pursue a GBS indication for current, off-label treatment options through this Committee's support and encouragement.

Additionally, given the importance of accurate patient diagnosis for nervous system disorders and the swift administration of the correct treatments which supply the best patient prognosis, we respectfully request the subcommittee recommendation for the Centers for Disease Control and Prevention to promote enhanced awareness and recognition activities of GBS and CIDP, in partnership with stakeholders.

This subcommittee's past investment in biomedical research has provided hope to the millions of patients with rare diseases which are difficult to diagnose, treat and prevent. I respectfully urge your continued support of important health related research and patient care programs at NIH and CDC. Thank you again for providing me with the opportunity to submit written testimony on behalf of the thousands of GBS and CIDP patients and their families and the GBS/CIDP Foundation, International.

PREPARED STATEMENT OF THE HARM REDUCTION COALITION

We thank you for the opportunity to submit testimony regarding fiscal year 2014 Appropriations. Our testimony focuses on the urgency of scaling up Federal overdose prevention efforts.

The Centers for Disease Control and Prevention (CDC) reports that "Drug overdose death rates in the United States have more than tripled since 1990 and have never been higher. In 2008, more than 36,000 people died from drug overdoses, and most of these deaths were caused by prescription drugs . . . there is currently a growing, deadly epidemic of prescription painkiller abuse . . . the misuse and abuse of prescription painkillers was responsible for more than 475,000 emergency department visits in 2009, a number that doubled in just 5 years."

A recent report published by the CDC demonstrates that overdose deaths continued to increase for the 11th consecutive year in 2010 and approximately 100 American lives were lost every single day. Overdose deaths continue to persist as a leading cause of preventable death in the United States.

The Obama Administration's 2013 National Drug Control Strategy prioritizes overdose prevention and intervention as a key component in addressing this public health epidemic. In order to meet the Administration's goal of reducing overdose deaths by 15 percent, the Office of National Drug Control Policy has emphasized the role of emergency opioid antagonist therapy in reducing mortality in their 2013 Strategy. "Naloxone is an opioid antagonist that has long been used as an emergency intervention to reverse the potentially fatal respiratory depressant effects of an opioid overdose (opioids include licit drugs such as morphine, codeine, oxycodone, methadone and hydrocodone as well as Schedule 1 illicit drugs such as heroin). Naloxone can be given by injection into a muscle or with a nasal spray in the nose. When administered to an individual who has taken opioids, it is believed naloxone dislodges the opioids from the opioid receptors in the brain. This can reverse the effects of an overdose and help restore breathing that may have stopped or slowed during the overdose episode. As death typically does not occur until several hours after an opioid overdose, there is a window of opportunity to intervene by calling 911, giving rescue breathing, and by the administration of naloxone by a trained lay person . . . Research has shown that naloxone is an important and cost-effective tool to prevent overdose and ultimately reduce drug use and its consequences."

However, despite the powerful life-saving properties of naloxone and overdose prevention education, it is underutilized. HHS, the Department of Justice, and other agencies have been working to address prescription drug misuse, abuse, and diversion, but there is no coordinated Federal public health effort focused specifically on preventing death from overdose and no Federal funding is currently being allocated to these evidence-based practices.

To that end, as advocates dedicated to preventing deaths from opioid overdose, we request that the subcommittee consider including report language in the fiscal year 2014 Appropriations bill which urges the Department of Health and Human Services and appropriate Federal agencies to adopt the following priorities:

1. Prioritize overdose prevention and intervention to receive current funding mechanisms and link to treatment and recovery services:

- Given the important role of the Substance Abuse Prevention and Treatment Block Grant in providing funding to single State agencies for prevention, treatment, and recovery services, the Substance Abuse and Mental Health Services Administration should take steps to encourage and support the use of Substance Abuse Prevention and Treatment Block Grant funds for opioid safety

education, training, and programming, with a focus on initiatives that distribute emergency opioid antagonist therapy to those likely to witness—and those at risk of—an overdose.

2. Take steps to increase awareness of—and access to—the use of opioid antagonist therapy:

- All Federal agencies involved in research, policies, regulation, and programs related to opioid misuse should coordinate efforts and develop and disseminate information about naloxone to health care professionals, individuals, and families and otherwise take other steps to facilitate its use, so that lives can be saved.
- The Department of Health and Human Services should coordinate a national public health campaign to increase awareness of the signs and symptoms of overdose and improve understanding of the steps that individuals can take to save the life of someone who is experiencing an overdose. Such a national campaign should include information regarding the use of naloxone, rescue breathing, and calling emergency services, such as 9-1-1 and/or poison control centers.
- CDC, working in collaboration with the Substance Abuse Mental Health Services Administration (SAMHSA) and the Health Resources and Services Administration (HRSA), should enable best practices, by providing technical assistance and toolkits for community programs and health professionals who wish to distribute naloxone.

3. Increase Federal surveillance and data collection regarding opioid use, misuse, and deaths to ensure that policies and programs are designed to target the actual causes of opioid misuse and death and to monitor the impact of recent State legislative actions that expand access and utilization of naloxone.

4. Continue Federal investment in the basic, clinical, and translational research supported by the National Institute of Drug Abuse (NIDA).

The Harm Reduction Coalition believes that these measures are critical to meeting the goal of reversing the overdose epidemic in the United States.

We thank you for your consideration of the important issues.

PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION
COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record recommending \$520 million in fiscal year 2014 for the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). HPNEC is an alliance of national organizations (<https://www.aamc.org/advocacy/hpniec/members.htm>) dedicated to ensuring the health care workforce is trained to meet the needs of the country's growing, aging, and diverse population.

Designed to provide education and training opportunities to aspiring health care professionals, in 2013, the programs celebrate 50 years of helping the workforce adapt to Americans' changing health care needs. With a focus on primary care, Titles VII and VIII are the only Federal programs designed to train providers in interdisciplinary, community-based settings to meet the needs of the country's special and underserved populations, increase minority representation in the health care workforce, and fill the gaps in the supply of health professionals not met by traditional market forces. Further, the programs are able to advance timely priorities, such as strengthening education and training opportunities in geriatrics to better care for the Nation's aging population and closing the gap in access to mental and behavioral health services.

While HPNEC recognizes the subcommittee faces difficult decisions in a constrained budget environment, a continued commitment to programs supporting health care workforce development should remain a high priority. The Nation faces a shortage of health professionals, and residents of underserved rural and urban areas alike already struggle to access health providers. Further, the number of Americans over age 65 is expected to reach 70 million by 2030, and as the Nation's baby boomers age, they will require more care. Coupled with the millions of newly insured individuals entering the system, this increased demand for health services will exacerbate the existing deficit of health professionals.

Diversifying the health care workforce is a central focus of the Title VII and VIII programs, making them a key player in the fight to mitigate racial, ethnic, and socio-economic health disparities, which cost the Nation billions of dollars each year. In particular, the Health Careers Opportunity Program (HCOP) trained 20 percent more minority and disadvantaged students than expected, helping students success-

fully complete their coursework and creating a more competitive health professions applicant pool.

Further, 1 in 3 Title VII and Title VIII program completers enter practice in a medically underserved community (MUC) or health professions shortage area (HPSA), helping to increase access to services in rural and urban underserved communities. Failure to fully fund the Title VII and VIII programs would jeopardize efforts to address these challenges and prepare the next generation of health professionals.

The Title VII and Title VIII programs can be considered in seven general categories:

- The Primary Care Medicine and Oral Health Training programs support education and training of primary care professionals, to improve access and quality of health care in underserved areas. Two-thirds of Americans interact with a primary care provider every year. Approximately one-half of primary care providers trained through these programs work in underserved areas, compared to 10 percent of those trained in other programs. The General Pediatrics, General Internal Medicine, and Family Medicine programs provide critical funding for primary care physician training in community-based settings and support a range of initiatives, including medical student and residency training, faculty development, and the development of academic administrative units. The primary care cluster also provides grants for Physician Assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. The General Dentistry, Pediatric Dentistry, and Public Health Dentistry programs provide grants to dental schools and hospitals to create or expand primary care and public health dental residency training programs.
- Because much of the Nation's health care is delivered in remote areas, the Interdisciplinary, Community-Based Linkages cluster supports community-based training of health professionals. These programs are designed to encourage health professionals to return to such settings after completing their training and to encourage collaboration between two or more disciplines. The Area Health Education Centers (AHECs) offer clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs, which leverage State and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners, including continuing education on a variety of topics such as cultural competence, health disparities, and issues affecting veterans. In the 2011–2012 academic year, AHECs trained more than 28,000 medical students in rural or underserved communities, half of which were located in a medically underserved community (MUC) and/or health professions shortage area (HPSA). Geriatric Health Professions programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, all designed to bolster the number and quality of health care providers caring for older generations, as well as faculty with geriatrics expertise. The Graduate Psychology Education program, which supports interdisciplinary training of doctoral-level psychology students with other health professionals, provides mental and behavioral health services to underserved populations (i.e., older adults, children, chronically ill, and victims of abuse and trauma, including returning military personnel and their families), especially in rural and urban communities. The Mental and Behavioral Health Education and Training Grant Program supports the training of psychologists, social workers, and child and adolescent professionals. These programs together work to close the gap in access to quality mental and behavioral health care services by increasing the number of trained mental and behavioral health providers.
- The Minority and Disadvantaged Health Professionals Training cluster helps improve health care access in underserved areas and the representation of minority and disadvantaged individuals in the health professions. Diversifying the health care workforce is a central focus of the programs, making them a key player in the fight to mitigate racial, ethnic, and socio-economic health disparities. Further, the programs emphasize cultural competency for all health professionals, an important role as the Nation's population is growing and becoming increasingly diverse. Minority Centers of Excellence support increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The Health Careers Opportunity Program seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The Faculty Loan Repayment and Faculty Fellowship

programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students.

- The Health Professions Workforce Information and Analysis program provides grants to institutions to collect and analyze data to advise future decision-making on the health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed valuable, policy-relevant studies on the distribution and training of health professionals, including the Eighth National Sample Survey of Registered Nurses, the Nation's most extensive and comprehensive source of statistics on registered nurses. Reflecting the need for better health workforce data to inform both public and private decisionmaking, the National Center for Workforce Analysis serves as a source of such analyses.
- The Public Health Workforce Development programs help increase the number of individuals trained in public health, identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health professionals by providing up-to-date training for current and future public health workers, particularly in underserved areas. Preventive Medicine Residencies, which do not receive funding through Medicare GME, provide training in the only medical specialty that teaches both clinical and population medicine to improve community health. This cluster also includes a focus on loan repayment as an incentive for health professionals to practice in disciplines and settings experiencing shortages. The Pediatric Subspecialty Loan Repayment Program offers loan repayment for pediatric medical subspecialists, pediatric surgical specialists, and child and adolescent mental and behavioral health specialists, in exchange for service in underserved areas.
- The Nursing Workforce Development programs under Title VIII provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. These programs provide the largest source of Federal funding for nursing education, providing loans, scholarships, traineeships, and programmatic support that, between fiscal year 2005 and 2010, supported over 400,000 nurses and nursing students as well as numerous academic nursing institutions and health care facilities. Each year, nursing schools turn away tens of thousands of qualified applications at all degree levels due to an insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. At the same time, the need for nursing services and licensed, registered nurses is expected to increase significantly over the next 20 years. The Advanced Education Nursing program awards grants to train a variety of nurses with advanced education, including clinical nurse specialists, nurse practitioners, certified nurse-midwives, nurse anesthetists, public health nurses, nurse educators, and nurse administrators. Workforce Diversity grants support opportunities for nursing education for students from disadvantaged backgrounds through scholarships, stipends, and retention activities. Nurse Education, Practice, and Retention grants help schools of nursing, academic health centers, nurse-managed health centers, State and local governments, and other health care facilities to develop programs that provide nursing education, promote best practices, and enhance nurse retention. The Loan Repayment and Scholarship Program repays up to 85 percent of nursing student loans and offers full-time and part-time nursing students the opportunity to apply for scholarship funds in exchange for 2 years of practice in a designated nursing shortage area. The Comprehensive Geriatric Education grants are used to train RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, train faculty members, and provide continuing education. The Nurse Faculty Loan program provides a student loan fund administered by schools of nursing to increase the number of qualified nurse faculty.
- The loan programs under Student Financial Assistance support financially disadvantaged health professions students. The Nursing Student Loan (NSL) is for undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans for financially needy health professions students based on institutional determination. These programs are funded out of each institution's revolving fund and do not receive Federal appropriations. The Loans for Disadvantaged Students program provides grants to in-

stitutions to make loans to health professions students from disadvantaged backgrounds.

By improving the supply, distribution, and diversity of the Nation's health care professionals, the Title VII and Title VIII programs not only prepare aspiring professionals to meet the Nation's workforce needs, but also help to improve access to care across all populations. Further, with the Bureau of Labor Statistics projecting that the health care industry will generate 3.2 million jobs through 2018 (more than any other industry), these programs can help individuals in reaching their career goals and communities in filling their health needs. The multi-year nature of health professions education and training, coupled with provider shortages across many disciplines and in many communities, necessitate a strong, continued, and reliable commitment to the Title VII and Title VIII programs.

While HPNEC members understand the immense fiscal pressures facing the subcommittee, we respectfully urge support for \$520 million for the Title VII and VIII programs. We look forward to working with the subcommittee to prioritize the health professions programs in fiscal year 2014 and into the future.

PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION

The HIV Medicine Association (HIVMA) of the Infectious Diseases Society of America (IDSA) represents more than 5,000 physicians, scientists and other health care professionals who practice on the frontline of the HIV/AIDS pandemic. Our members provide medical care and treatment to people with HIV/AIDS throughout the U.S., lead HIV prevention programs and conduct research to develop effective HIV prevention and treatment options. We work in communities across the country and around the globe as medical providers and researchers dedicated to the field of HIV medicine.

We recognize the difficult fiscal environment Congress is facing. However, as you make tough spending decisions for fiscal year 2014, we strongly urge you to maintain adequate funding for critical HIV/AIDS treatment, prevention and research programs. Our past investment in HIV-related research has supported critical discoveries that now allow leaders worldwide to envision a world without AIDS.

Despite our remarkable progress in HIV prevention, diagnosis and treatment, HIV/AIDS remains a serious and significant epidemic in the United States with a record 1.2 million people living with HIV and an estimated 50,000 new infections occurring annually. HIV disease disproportionately impacts racial and ethnic minority communities and low income people who depend on public services for their life-saving health care and treatment. Early and reliable access to HIV care and treatment help patients with HIV live healthy and productive lives and is cost effective. In addition, having persons living with HIV virologically suppressed on antiretroviral therapy decreases transmission of HIV and thus is critical in curbing the epidemic. The comprehensive, expert HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population. In fact, Ryan White funded clinics have become models for "medical homes". Once in care, patients who attend at least one Ryan White medical visit do well—with 70 percent of those on antiretroviral treatment having undetectable levels of the virus in their blood. This is much higher than the estimate from the CDC that just 25 percent of people living with HIV in the U.S. are virally suppressed. The annual health care costs for HIV patients who are not able to achieve viral suppression (often due to delayed diagnosis and care) are nearly 2.5 times that of healthier HIV patients.

In order to dramatically change the trajectory of the HIV epidemic in the U.S. and around the world, we strongly urge you to support at minimum the President's proposed fiscal year 2014 funding levels for the Centers for Disease Control and Prevention (CDC)'s HIV and STD prevention programs and the Ryan White Program at the Health Resources and Services Administration, as well as the President's fiscal year 2014 request level for the medical research supported by the National Institutes of Health, including the President's proposed \$47 million increase for HIV/AIDS research across the institutes and centers. Failure to maintain adequate funding for these critical priorities will set us back in the fight against HIV infection and harm the Nation's health and fiscal well-being. The funding requests in our testimony largely reflect the consensus of the Federal AIDS Policy Partnership (FAPP), a coalition of HIV organizations from across the country, and are estimated to be the amounts necessary to strengthen our investment in combatting HIV disease and meet the need in communities across the country.

Health Care Reform.—We strongly support at a minimum the President's fiscal year 2014 request level for health care reform discretionary funding under the Pa-

tient Protection and Affordable Care Act (ACA). Of particular importance is funding to support health care workforce education and training programs under Titles VII and VIII of the Public Health Service Act (PHSA); health care quality improvement programs, and the Medicare and Medicaid demonstration programs.

If we are to succeed in improving the quality and efficiency of our health care delivery system while addressing health care costs, it is essential to fully fund the Centers for Medicare and Medicaid Innovation (CMMI). In particular, we would hope to see CMMI evaluate the health outcomes and cost effectiveness of managing the care of people with HIV through “patient centered medical homes.” HIV disease is included among the qualifying chronic disease conditions under the new State Medicaid Health Home option that allows Medicaid enrollees with at least two chronic conditions to designate a provider as a health home. Since a majority of people with HIV rely on Medicaid for their health care coverage, it is vital that this model of care is pilot-tested and supported by Medicaid programs.

HIV/AIDS Bureau of the Health Resources and Services Administration.—We strongly urge you to increase funding for the Ryan White Program by \$276 million in fiscal year 2014 with at least an increase of \$21.5 million over the fiscal year 2013 continuing resolution level for Part C. Ryan White Part C funds comprehensive HIV care and treatment—services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care available at Part-C funded programs (excluding medications), including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers a small percentage of the total cost of providing comprehensive care with some programs receiving \$450 or lower per patient per year to cover care. The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but efforts to bring more people with HIV into care through routine HIV screening along with ongoing economic pressures are creating a crisis in communities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities. At a bare minimum, we strongly urge you to support an increase of \$20 million over fiscal year 2013 appropriated funding for Ryan White Part C.

Center for Disease Control and Prevention’s (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP).—HIVMA strongly urges total fiscal year 2014 funding of \$1.424 billion for the CDC’s NCHHSTP, an increase of \$314 million over the fiscal year 2013 level, including increases of: \$180 million for HIV prevention and surveillance, \$5.3 million for viral hepatitis and \$102.7 million for Tuberculosis prevention.

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. The CDC estimates that the 50,000 new HIV infections each year in the U.S. may result in \$56 billion in medical care and lost productivity costs. Despite the known benefit of effective treatment, nearly 20 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within 1 year of diagnosis. A sustained commitment to HIV prevention funding is critical to enhance HIV/AIDS surveillance and expand HIV testing and linkage to care, in order to lower HIV incidence and prevalence in the U.S. Particularly in light of steep State budget cuts, a failure to invest now in HIV prevention will be costly. At a bare minimum we strongly urge the Committee to at least support an increase of \$180 million for HIV prevention and an increase of \$5.3 million for viral hepatitis at the CDC. We also support a funding level of at least \$363 million for CDC’s global health programs, which includes resources for the agency’s essential role in implementing PEPFAR programs in developing nations.

Agency for Health Care Quality and Research (AHRQ).—HIVMA urges the Committee to provide \$2 million for the HIV Research Network (HIVRN). The HIVRN is a consortium of 19 HIV primary care sites co-funded by AHRQ and HRSA to evaluate health care utilization and clinical outcomes in HIV infected children, adolescents and adults in the U.S. The Network analyzes and disseminates information on the delivery and outcomes of health care services to people with HIV infection. These data help to improve delivery and outcomes of HIV care in the U.S. and to identify and address disparities in HIV care that exist by race, gender, and HIV risk factor. The HIVRN is a valuable and highly utilized source of information on the cost and cost-effectiveness of HIV care in the U.S. at a time when such data is particularly needed to inform health systems reform and the development and implementation of a National HIV/AIDS Strategy.

National Institutes of Health (NIH)—Office of AIDS Research (OAR).—HIVMA strongly supports an fiscal year 2014 funding level of \$36 billion for the NIH, including \$3.6 billion for the NIH Office of AIDS Research. This level of funding is vital to sustain the pace of research that will improve the health and quality of life for millions of men, women and children in the U.S. and in the developing world. Our past investment in a comprehensive portfolio was responsible for the dramatic gains that we made in our HIV knowledge base, gains that resulted in reductions in mortality from AIDS of nearly 80 percent in the U.S. and in other countries where treatment is available. Gains that also helped us to reduce the mother to child HIV transmission rate from 25 percent to less than 1 percent in the U.S. and to very low levels in other countries where treatment is available.

Strong, sustained NIH funding is a critical national priority that will foster better health, economic revitalization and an effective National HIV/AIDS Strategy. In every State across the country, the NIH supports research at hospitals, universities and medical schools, and community based service organizations. This includes the creation of jobs that will be essential to future discovery. Sustained increases in funding are also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries.

The benefits of HIV research are far reaching. Researchers have applied HIV research methods and findings to studying and treating other serious conditions, such as cancer, and hepatitis B and C virus. Congress should ensure the Nation does not delay vital HIV/AIDS research progress. We must increase HIV/AIDS research funding to sustain medical research capacity and maintain our worldwide leadership in HIV/AIDS research leadership and innovation.

Policy Riders—Remove the Harmful Ban on Federal Funding for Syringe Exchange Programs.—HIVMA strongly urges adoption of language included in the President's fiscal year 2014 budget that would re-instate language previously enacted into law in fiscal year 2010 and fiscal year 2011 allowing Federal funding to be used for syringe exchange programs. Such action will support local control by letting local communities make their own decisions about how best to prevent new HIV and viral hepatitis infections. It is well proven that syringe exchange programs are a cost-effective means to lower rates of HIV/AIDS and viral hepatitis, reduce the use of illegal drugs and help connect people to medical treatment, including substance abuse treatment. We cannot afford to dismiss any of the scientifically proven tools in the HIV prevention tool box if we are going to end AIDS in the U.S. and around the globe.

CONCLUSION

Historically, our Nation has made significant strides in responding to the HIV pandemic here at home and around the world, but we have lost ground in recent years, as funding priorities have shifted away from public health and research programs. We appreciate the many difficult decisions that Congress faces this year, but urge you to recognize the importance of investing in HIV prevention, treatment and research now to avoid the much higher cost that individuals, communities and broader society will incur if we fail to support these programs. We must seize the opportunity to limit the toll of this deadly infectious disease on our planet, to save the lives of millions who are infected or at risk of infection here in the U.S. and around the globe, and to realize the vision of an AIDS-free generation.

PREPARED STATEMENT OF THE HUMANE SOCIETY OF THE UNITED STATES AND HUMANE SOCIETY LEGISLATIVE FUND

On behalf of The Humane Society of the United States (HSUS) and the Humane Society Legislative Fund (HSLF), we appreciate the opportunity to provide testimony on our top NIH funding priorities for the House Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee in fiscal year 2014.

SUPPORT OF FEDERALLY OWNED CHIMPANZEES IN SANCTUARY

The HSUS and HSLF request that Congress address budget issues currently restricting chimpanzee sanctuary expenditures so that the National Institutes of Health can make cost-effective and humane decisions regarding the care of these animals.

In 2000, Congress passed the Chimpanzee Health Improvement Maintenance and Protection Act (CHIMP Act) that established the national chimpanzee sanctuary system for chimpanzees no longer used in research and included a \$30 million cap

on related Federal expenditures. No such cap exists for spending on maintaining chimpanzees in laboratories—a more expensive and less humane form of housing. Unfortunately, the sanctuary expenditure cap is about to be reached, at just the moment when NIH is poised to declare that nearly all federally-owned chimpanzees should be retired to sanctuary. This crisis can be averted by enacting a sentence (see Language Requested below) in the final fiscal year 2014 budget.

Further basis of our request can be found below.

Background Cost Information

Currently, NIH owns approximately 580 chimpanzees and is responsible for their lifetime care and support. Of those chimpanzees, roughly 360 continue to be housed in laboratories. According to an independent economic analysis conducted for The HSUS in 2012, the average per diem cost to taxpayers of maintaining a chimpanzee in a laboratory is \$60. The per diem cost to taxpayers of caring for a chimpanzee in the national sanctuary system during the same time was \$44. As a result of economies of scale, the per diem for sanctuary care is projected to decrease to \$32 per chimpanzee with the addition of 100 chimpanzees.¹

Given that chimpanzees can live up to 60 years in captivity, the difference in per diem costs can add up quickly. The Government would save a substantial amount of money over time by moving the Government owned chimpanzees to the national sanctuary.

Chimpanzees are not necessary for most research

In December of 2011, the Institute of Medicine (IOM) and National Research Council released a report which found that chimpanzees are “largely unnecessary” for research and, further, could not identify any current area of research for which chimpanzees are essential. The report also called for a sharp reduction in the use of chimpanzees in research and noted that the “current trajectory indicates a decreasing scientific need for chimpanzee studies due to the emergence of non-chimpanzee models and technologies.”²

Following that report, the National Institutes of Health immediately accepted the IOM findings and created an independent Council of Councils Working Group of experts to advise the agency on implementation of the findings. After nearly a year of deliberations, the Working Group presented their recommendations in January 2013. Among other things, the recommendations included the retirement of the majority of the more than 350 Government-owned chimpanzees currently in laboratories to sanctuary, a substantial decrease in the number of Government funded grants involving chimpanzees in laboratories and no revitalization of chimpanzee breeding for research purposes.³

The NIH is expected to make a final decision on the recommendations in the very near future. But, given the consistent results of the IOM and NIH Working Group reports, it's safe to anticipate that a large number of chimpanzees will be retired in the near future. By including the language suggested here, Congress can ensure cost-effective sanctuary space is available so NIH is not forced to maintain retired chimpanzees in more expensive laboratories.

Ethologically appropriate chimpanzee housing only available in sanctuary

In addition to their other findings, the IOM committee stated that chimpanzees used in research should be kept in “ethologically appropriate physical and social environments.” However, the concept was not clearly defined in the IOM report. Therefore, the NIH Council of Councils Working Group produced several recommendations to more clearly define “ethologically appropriate” environments for chimpanzees.² Those recommendations included providing large, complex social groups, year round outdoor access and more than 1,000 square feet of living space per chimpanzee, among other things. Importantly, no laboratory meets the Working Group's definition of “ethologically appropriate” and the report described the national sanctuary system as the “most species-appropriate environment currently available.”³

Upgrading laboratories to meet the needs of chimpanzees would be extremely expensive and, given the lack of necessity for chimpanzees in research, a waste of tax-

¹Phillips, Carl for The Humane Society of the United States (2012) Federal Government budget savings from defunding invasive research on chimpanzees and retiring Government-owned laboratory chimpanzees to sanctuary [white paper].

²Institute of Medicine and National Research Council. (2011). Chimpanzees in Biomedical and Behavioral Research: Assessing the Necessity. National Academies Press: Washington, D.C.

³2013 Report of the National Institutes of Health Council of Councils Working Group on the Use of Chimpanzees in NIH-Supported Research.

payer dollars. It makes fiscal sense to send retired chimpanzees to sanctuary where they will receive optimal care at a lower cost than in laboratories.

Ethical and public concerns

Americans are clearly concerned about the use of chimpanzees in research and believe that chimpanzees deserve sanctuary. A national poll found that 74 percent support permanent retirement to sanctuaries for chimpanzees no longer used in experiments; 71 percent believe that chimpanzees who have been in the laboratory for over 10 years should be sent to sanctuary for retirement⁴; and 54 percent believe that it is unacceptable for chimpanzees to “undergo research which causes them to suffer for human benefit.”⁵

We respectfully request the following bill language: “Funds provided to the National Institutes of Health in this and subsequent acts may be used to support the Sanctuary System for Surplus Chimpanzees authorized by section 404K of the Public Health Service Act, including for the construction, renovation, and funding of current or additional facilities of the sanctuary system as authorized by section 404K, notwithstanding the limitations in subsection (g) of such section.”

We appreciate the opportunity to share our views for the Labor, Health and Human Services, Education and Related Agencies Appropriations Act for fiscal year 2014. We hope the Committee will be able to accommodate this modest request that will save the Government a substantial sum of money, benefit chimpanzees, and allay some concerns of the public at large. Thank you for your consideration.

RECOMMENDATIONS OF THE COUNCIL OF COUNCILS WORKING GROUP ON THE USE OF CHIMPANZEES IN NIH-SUPPORTED RESEARCH

As was discussed above, in their December 2011 report entitled *Chimpanzees in Biomedical and Behavioral Research: Assessing the Necessity*, the Institute of Medicine found that chimpanzees are “largely unnecessary” for current research. Following the IOM report, the National Institutes of Health commissioned an independent Working Group of experts to advise them on how to implement the findings of the IOM report. The Working Group released their recommendations in January 2013.

These recommendations include retiring the majority of federally owned chimpanzees to sanctuary, a clear set of criteria for housing and maintaining chimpanzees in a manner appropriate to the needs of the species, a decrease in grants for chimpanzee research, a rigorous review process for protocols to ensure that any future research conducted on chimpanzees is necessary, a cessation of breeding for research and an increased investment in alternatives to chimpanzee use. The Working Group has also recommended that a small number of chimpanzees be available for research in the unlikely event of a new or reemerging threat that requires it. However, the Working Group advised that these chimpanzees be kept in ethologically appropriate conditions and that the need for this group should be reassessed frequently.

By adopting these recommendations, NIH will not only free up funds that would otherwise be spent on unnecessary chimpanzee research to be spent on research that is more relevant to human health, it will save taxpayer dollars by retiring the chimpanzees into the less-costly sanctuary system, providing them with optimal care.

We respectfully request the following committee report language: “The Committee thanks the National Institutes of Health for their thorough review of the use of chimpanzees in research and supports the acceptance and implementation of the recommendations proposed by the NIH Council of Councils Working Group on the Use of Chimpanzees in NIH-supported Research. In particular, we urge implementation of those recommendations related to the retirement to sanctuary of hundreds of government-owned chimpanzees, phasing out of current biomedical research on chimpanzees, meeting standards for ethologically appropriate physical and social environments for chimpanzees, prohibiting NIH financial support for chimpanzee breeding, creation of an independent Oversight Committee to ensure a proper and transparent review of any future uses of chimpanzees in government-funded research and increased funding for alternative research methods. These recommendations are in the best interests of human health and chimpanzee welfare. They will also result in significant taxpayer savings because care in ethologically appropriate sanctuaries is less expensive than care in laboratories and, further, the federal gov-

⁴ 2006 poll conducted by the Humane Research Council for Project Release & Restitution for Chimpanzees in laboratories.

⁵ 2001 poll conducted by Zogby International for the Chimpanzee Collaboratory.

ernment will no longer be footing the bill for unnecessary and costly research protocols and breeding programs.”

HIGH THROUGHPUT SCREENING, TOXICITY PATHWAY PROFILING, AND BIOLOGICAL INTERPRETATION OF FINDINGS

NATIONAL INSTITUTES OF HEALTH—OFFICE OF THE DIRECTOR

In 2008, NIH, NIEHS and EPA signed a memorandum of understanding (MOU) to collaborate with each other to identify and/or develop high throughput screening assays that investigate “toxicity pathways” that contribute to a variety of adverse health outcomes (e.g., from acute oral toxicity to long-term effects like cancer). In addition, the MOU recognized the necessity for these Federal research organizations to work with “acknowledged experts in different disciplines in the international scientific community.” Much progress has been made, including FDA joining the MOU, but there is still a significant amount of research, development and translational science needed to bring this vision forward to where it can be used with confidence for safety determinations by regulatory programs in the Government and product stewardship programs in the private sector. In particular, there is a growing need to support research to develop the key science-based interpretation tools which will accelerate our understanding of the human mind.” According to the White House, the Office of the Director at NIH can play a leadership role for the entire U.S. Government by funding both extramural and intramural research.

In April, 2013, the Obama Administration announced an initiative to map the human brain, Brain Research through Advancing Innovative Neurotechnologies (BRAIN), which the White House describes as “a bold new research effort to revolutionize our understanding of the human mind.” According to the White House, the Brain Initiative will “. . . accelerate the development and application of new technologies that will enable researchers to produce dynamic pictures of the brain that show how individual brain cells and complex neural circuits interact at the speed of thought.”⁶ The goals of this initiative are to shed light on normal brain function as well as understanding the development of neurological diseases such as Alzheimer’s and Parkinson’s, childhood developmental issues such as autism, and acute events such as stroke—and hopefully find new ways of treating them.

We respectfully request the following committee report language, which is supported by The HSUS, HSLF and the American Chemistry Council:

NIH Director

“The Committee supports NIH’s leadership role in the creation of a new paradigm for chemical risk assessment based on the incorporation of advanced molecular biological and computational methods in lieu of animal toxicity tests. NIH has indicated that development of this science is critical to several of its priorities, from personalized medicine to tackling specific diseases such as cancer and diabetes and including critical initiatives such as BRAIN. The Committee encourages NIH to continue to expand both its intramural and extramural support for the use of human biology-based experimental and computational approaches in health research to further define human biology, disease pathways and toxicity and to develop tools for their integration into evaluation strategies. Extramural and intramural funding should be made available for the evaluation of the relevance and reliability of human biology-based and Tox21-related methods and prediction tools to assure readiness and utility for regulatory purposes, including pilot studies of pathway-based risk assessments. The Committee requests NIH provide a report on associated funding in FY 2014 for such activity and a progress report of related activities in the congressional justification request, featuring a 5-year plan for projected budgets for the development of human biology-based and Tox21-related methods, including prediction models, and activities specifically focused on establishing scientific confidence in them for regulatory use. The Committee also requests NIH prioritize an additional (1–3%) of its research budget within existing funds for such activity.”

PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA

The Infectious Diseases Society of America (IDSA) represents more than 10,000 infectious diseases (ID) physicians and scientists devoted to patient care, prevention,

⁶Boseley, S. 2013. Obama unveils brain mapping initiative and calls for further research. The Guardian, Tuesday 2 April 2013. <http://www.guardian.co.uk/science/2013/apr/02/obama-brain-initiative-fight-disease>.

public health, education, and research. Investment in ID research and public health efforts can reduce health care costs, save lives, and create jobs. IDSA urges you to provide strong funding for the Department of Health and Human Services' (HHS) National Institutes of Health, Centers for Disease Control and Prevention, Office of the Assistant Secretary for Preparedness and Response, and Biomedical Advanced Research and Development Authority as well as adopt appropriate report language for the Centers for Medicare and Medicaid Services.

NATIONAL INSTITUTES OF HEALTH (NIH)

NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID)

IDSA recommends that the subcommittee continue to invest strongly in medical research funding at the NIH, and at NIAID, in particular, so that patients may continue to benefit from the life-saving benefits that medical research affords. In April, IDSA released an updated report on the dire status of the antibiotic pipeline, which found only seven (7) antibiotics to treat Gram-negative bacteria, which represent the most urgent needs, in Phase II development or later. Given the growing crisis related to antibiotic-resistant infections and the lack of new antibiotics in development (read more at www.AntibioticsNow.org), we believe it is particularly imperative that NIAID invest more vigorously in antibacterial resistance research, including related diagnostics research, so that our Nation can better respond to these dangerous and expensive pathogens, which threaten patient care, public health and national security. Our funding goal for NIAID's antibacterial resistance and related diagnostics efforts is at least \$500 million annually by the end of fiscal year 2014. As part of this effort, we believe NIAID should invest at least \$100 million/year in the antibiotic-resistance focused clinical trials network that the institute now is establishing and which should be up and running in 2014. NIAID should be applauded for establishing this new network, but unfortunately, the planned investment of \$10 million/year over the next 7 years will not be sufficient to undertake the critical studies needed to address what are quickly becoming untreatable infections.

The subcommittee also should adopt report language urging NIAID to invest in research on new antiviral drugs and related diagnostics that are effective against emerging drug-resistant influenza variants. The dearth of novel antiviral influenza drugs is of concern, especially as resistance grows.

IDSA also urges the subcommittee to restore the salary cap for NIH grantees to Executive Level I. The salary cap reduction enacted in fiscal year 2012 disproportionately affects physician-investigators and serves as a deterrent to their recruitment into research careers.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

NATIONAL CENTER FOR EMERGING AND ZOOONOTIC INFECTIOUS DISEASES (NCEZID)

IDSA supports strong funding for NCEZID, which houses CDC's antimicrobial resistance activities. We must be able to track resistance, understand its driving factors and measure the impact of efforts to limit resistance. State and local public health laboratories are key, but they depend largely upon CDC for funding, and currently only about half of them can provide some level of antimicrobial susceptibility testing. NCEZID also needs strong funding to enhance data collection on antimicrobial use and to promote the uptake of antimicrobial stewardship programs to help protect the effectiveness of these precious drugs. In particular, IDSA urges the subcommittee to fully fund two requests in the President's budget proposal: (1) the Advanced Molecular Detection (AMD) initiative and (2) the National Healthcare Safety Network (NHSN). AMD is a necessary and overdue effort that will allow CDC to more quickly determine the origin of emerging diseases, whether microbes are resistant to antibiotics, and how microbes are moving through a population. The AMD initiative will strengthen CDC's epidemiologic and laboratory expertise to effectively guide public health action. Additional funding for NHSN will allow CDC to further invest in the EpiCenters—five academic centers which conduct research projects on health care-associated infections and antibiotic-resistant infections. The EpiCenters have survived on a \$2 million budget over the past 15 years with no increase. Critical areas where the EpiCenters could expand their work include: evaluating interventions to prevent or limit the development of antimicrobial resistance, facilitating public health research on the prevention and control of resistant organisms, and assessing the appropriateness of surveillance and prevention programs in health care and institutional settings. IDSA also urges strong funding for the Emerging Infections Program (EIP) to assess the epidemiology of emerging resistant pathogens in infectious diseases of public health importance.

IDSA also encourages the subcommittee to adopt antimicrobial resistance report language to encourage the following activities to the extent possible given the current budgetary constraints:

- Urging CDC to implement prevention collaboratives with State health departments to prevent the transmission of significant resistant pathogens across health care settings.
- Encouraging CDC to expand academic public health partnerships through the EpiCenters.
- Recommending CDC pilot and test quality measures to help measure antimicrobial use.

NATIONAL CENTER FOR IMMUNIZATION AND RESPIRATORY DISEASES (NCIRD)

IDSA recommends strong funding for NCIRD, including the Section 317 Immunization Program. The Society remains concerned that the Administration once again has proposed decreasing immunizations funding. Even with implementation of expanded immunizations coverage under the Affordable Care Act, immunization funding through CDC is needed to help providers obtain and store vaccines; establish and maintain vaccine registries; provide education about vaccines; and promote vaccination of health care workers. IDSA recommends report language urging CDC to work with State and local governments to ensure immunization recommendations, defined by the Advisory Committee on Immunization Practices (ACIP), are implemented except when medically-contraindicated.

Given that recent outbreaks of pertussis (whooping cough) are among the largest in the U.S. during the past half century, it is particularly important to ensure that more individuals receive this vaccination.

Also worrisome, influenza vaccination rates among health care workers overall remained stagnant in 2012. Funding to address this issue is critical to protect the health of those individuals most needed to respond to influenza outbreaks and pandemics and to protect patients at risk of infection.

IDSA strongly supports the President's proposed funding increase for influenza preparedness activities. In IDSA's recently updated Pandemic and Seasonal Influenza Principles for United States Action, the Society recommends strong funding for such activities, including public health infrastructure and countermeasures as well as long-term governmental coordination and planning. Lack of sufficient funding could lead to an increased incidence and severity of influenza, hospitalization costs and mortality.

Recent infectious outbreaks have underscored the need for a strong investment to maintain our capacity to detect and respond to emergencies as they occur, such as the fungal meningitis outbreak caused by a contaminated steroid product that killed more than 50 people, and emerging H7N9 influenza in China, as well as infectious threats associated with disasters such as Hurricanes Katrina and Sandy. Funding is needed to provide coordination, guidance and technical assistance to State and local governments; support the Strategic National Stockpile; strengthen and sustain epidemiologic and public health laboratory capacity; and provide clear and effective communications during an emergency.

THE NATIONAL CENTER FOR HIV, VIRAL HEPATITIS, STD AND TB PREVENTION (NCHHSTP)

IDSA strongly urges total fiscal year 2014 funding of \$1.424 billion for the CDC's NCHHSTP, an increase of \$314 million over the fiscal year 2013 level, including increases of: \$180 million for HIV prevention and surveillance, \$5.3 million for viral hepatitis and \$102.7 million for Tuberculosis prevention.

Every nine and a half minutes a new HIV infection happens in the U.S. with more than 60 percent of new cases occurring among African Americans and Hispanic/Latinos. The CDC estimates that the 50,000 new HIV infections each year in the U.S. may result in \$56 billion in medical care and lost productivity costs. Despite the known benefit of effective treatment, nearly 20 percent of people living with HIV in the U.S. are still not aware of their status and as many as 36 percent of people newly diagnosed with HIV progress to AIDS within 1 year of diagnosis. A sustained commitment to HIV prevention funding is critical to enhance HIV/AIDS surveillance and expand HIV testing and linkage to care, in order to lower HIV incidence and prevalence in the U.S. Particularly in light of steep State budget cuts, a failure to invest now in HIV prevention will be costly. At a bare minimum we strongly urge the Committee to at least support an increase of \$180 million for HIV prevention and an increase of \$5.3 million for viral hepatitis at the CDC. We also support a funding level of at least \$363 million for CDC's global health programs, which includes resources for the agency's essential role in implementing PEPFAR programs in developing nations.

A strong investment is needed to implement CDC's new hepatitis C screening policy, including funding to support education, testing, referral, vaccination and surveillance. Hepatitis B and C affect nearly six million Americans, the vast majority of whom do not know they are infected. These infections lead to chronic liver disease, with a loss of 15,000 lives each year,¹ liver cancer, and increased transplantations for those suffering liver failure.

IDSA recommends strong funding to support Federal, State, and local health tuberculosis (TB) detection, treatment, and prevention efforts. Adequate funding also must be directed to the TB Trials Consortium that is testing new TB therapeutics—an urgent need as the threat of drug-resistant TB grows.

ASSISTANT SECRETARY FOR PREPAREDNESS AND RESPONSE (ASPR)

In addition to strongly investing in ASPR's critical preparedness and response activities, IDSA urges the subcommittee to adopt report language to encourage the development of clear Federal guidelines for conducting research during a public health emergency. Specifically, report language should urge the ASPR to include the Office for Human Research Protections (OHRP) and other HHS offices and agencies involved in public health emergency research in the ASPR-led discussions concerning a public health emergency research review board. Also, ASPR should issue appropriate provisions and guidances to reduce ambiguity and improve harmonization among various agencies.

BIOMEDICAL ADVANCED RESEARCH AND DEVELOPMENT AUTHORITY (BARDA)

IDSA supports robust funding for BARDA to facilitate advanced research and development (R&D) of medical countermeasures, including therapeutics, diagnostics, vaccines, and other technologies, including new antibiotics to address both intentional attacks and naturally emerging infections. BARDA is a critical source of funding for public-private collaborations for antibiotic R&D.

INDEPENDENT STRATEGIC INVESTMENT FIRM

IDSA supports the establishment and funding of the Medical Countermeasure Strategic Investor (MCMSI), proposed by the ASPR in August 2010 and again included in the President's fiscal year 2014 budget request. The MCMSI would be a non-government, non-profit entity that would partner with small "innovator" companies and private investors to address urgent needs, including the development of novel antimicrobials.

CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)

IDSA urges the subcommittee to adopt report language urging CMS to help address the growing problem of antimicrobial resistance by working with healthcare institutions to develop and implement physician-led antimicrobial stewardship programs in all healthcare facilities.

Moreover, we ask for report language that supports the submission by acute care hospitals of summary data on influenza vaccination of health care personnel and the expansion of this requirement to all hospitals and nursing facilities.

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

HIV/AIDS BUREAU

IDSA strongly urges the subcommittee to increase funding for the Ryan White Program by \$276 million in fiscal year 2014 with at least an increase of \$21.5 million over the fiscal year 2013 continuing resolution level for Part C. Ryan White Part C funds comprehensive HIV care and treatment—services that are directly responsible for the dramatic decreases in AIDS-related mortality and morbidity over the last decade. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care available at Part-C funded programs (excluding medications), including lab work, STD/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management. Part C funding covers a small percentage of the total cost of providing comprehensive care with some programs receiving \$450 or lower per patient per year to cover care. The HIV medical clinics funded through Part C have been in dire need of increased funding for years, but efforts to bring more people with HIV into care through routine HIV screening along with ongoing economic pressures are creating a crisis in commu-

¹ "Combating the Silent Epidemic of Viral Hepatitis: Action Plan for the Prevention, Care and Treatment of Viral Hepatitis," U.S. Department of Health and Human Services (May, 2011).

nities across the country. An increase in funding is critical to prevent additional staffing and service cuts and ensure the public health of our communities. At a bare minimum, IDSA strongly urges you to support an increase of \$20 million over fiscal year 2013 appropriated funding for Ryan White Part C.

Thank you again for the opportunity to submit this statement on behalf of the Nation's infectious diseases physicians and scientists. Forward any questions to ajezeke@idsociety.org.

PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL
GASTROINTESTINAL DISORDERS

- 1) \$32 billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2012. Increase funding for the National Cancer Institute (NCI), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Allergy and Infectious Diseases (NIAID) by 12 percent.
 - 2) Continue focus on Digestive Disease Research and Education at NIH, including, Irritable Bowel Syndrome (IBS), Fecal Incontinence Gastroesophageal Reflux Disease (GERD) Gastroparesis, and Cyclic Vomiting Syndrome (CVS).
-

Thank you for the opportunity to present the views of the International Foundation for Functional Gastrointestinal Disorders (IFFGD) regarding the importance of functional gastrointestinal and motility disorders (FGIMD) research. Established in 1991, IFFGD is a patient-driven nonprofit organization dedicated to assisting individuals affected by FGIMDs, and providing education and support for patients, healthcare providers, and the public. IFFGD also works to advance critical research on FGIMDs in order to develop better treatment options and to eventually find cures. IFFGD has worked closely with the National Institutes of Health (NIH) on many priorities, and I served on the National Commission on Digestive Diseases (NCDD), which released a long-range plan in 2009, entitled Opportunities and Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases.

The need for increased research, more effective and efficient treatments, and the hope for discovering a cure for FGIMDs are close to my heart. My own experiences of suffering from FGIMDs motivated me to establish IFFGD, and I was shocked to discover that despite the high prevalence of FGIMDs among all demographic groups, such a lack of research existed. This translates into a dearth of diagnostic tools, treatments, and patient supports. Even more shocking is the lack of awareness among the medical community and the public, leading to significant delays in diagnosis, frequent misdiagnosis, and inappropriate treatments including unnecessary surgery. Most FGIMDs have no cure and limited treatment options, so patients face a lifetime of chronic disease management. The costs associated with these diseases range from \$25–\$30 billion annually; economic costs are also reflected in work absenteeism and lost productivity.

IRRITABLE BOWEL SYNDROME (IBS)

IBS affects 30 to 45 million Americans, conservatively at least 1 out of every 10 people. It is a chronic disease that causes abdominal pain and discomfort associated with a change in bowel pattern, such as diarrhea and/or constipation. As a “functional disorder,” IBS affects the way the muscles and nerves work, but the bowel does not appear to be damaged on medical tests. Without a diagnostic test, IBS often goes undiagnosed or misdiagnosed for years. Even after IBS is identified, treatment options are limited and vary from patient to patient. Due to persistent pain and bowel unpredictability, individuals may distance themselves from social events and work. Stigma surrounding bowel habits may act as barrier to treatment, as patients are not comfortable discussing their symptoms with doctors. Many people also dismiss their symptoms or attempt to self-medicate with over-the-counter medications. Outreach to physicians and the general public remain critical to overcome these barriers to treatment and assist patients.

FECAL INCONTINENCE

At least 12 million Americans suffer from fecal incontinence. Incontinence crosses all age groups, but is more common among women and the elderly of both sexes. Often it is associated with neurological diseases, cancer treatments, spinal cord injuries, multiple sclerosis, diabetes, prostate cancer, colon cancer, and uterine cancer.

Causes of fecal incontinence include: damage to the anal sphincter muscles, damage to the nerves of the anal sphincter muscles or the rectum, loss of storage capacity in the rectum, diarrhea, or pelvic floor dysfunction. People may feel ashamed or humiliated, and most attempt to hide the problem for as long as possible. Some don't want to leave the house in fear they might have an accident in public; they withdraw from friends and family, and often limit work or education efforts. Incontinence in the elderly is the primary reason for nursing home admissions, an already significant social and economic burden in our aging population. In 2002, IFFGD sponsored a consensus conference entitled, Advancing the Treatment of Fecal and Urinary Incontinence Through Research: Trial Design, Outcome Measures, and Research Priorities. IFFGD also collaborated with NIH on the NIH State-of-the-Science Conference on the Prevention of Fecal and Urinary Incontinence in Adults in 2007.

NIDDK recently launched a Bowel Control Awareness Campaign (BCAC) that provides resources for healthcare providers, information about clinical trials, and advice for individuals suffering from bowel control issues. The BCAC is an important step in reaching out to patients, and we encourage continued support for this campaign. Further research on fecal incontinence is critical to improve patient quality of life and implement the research goals of the NCDD.

GASTROESOPHAGEAL REFLUX DISEASE (GERD)

GERD is a common disorder which results from the back-flow of stomach contents into the esophagus. GERD is often accompanied by chronic heartburn and acid regurgitation, but sometimes the presence of GERD is only revealed when dangerous complications become evident. There are treatment options available, but they are not always effective and may lead to serious side effects. Gastroesophageal reflux (GER) affects as many as one-third of all full term infants born in America each year and even more premature infants. GER results from immature upper gastrointestinal motor development. Up to 8 percent of children and adolescents will have GER or GERD due to lower esophageal sphincter dysfunction and may require long-term treatment.

GASTROPARESIS

Gastroparesis, or delayed gastric emptying, refers to a stomach that empties slowly. Gastroparesis is characterized by symptoms from the delayed emptying of food, namely: bloating, nausea, vomiting, or feeling full after eating only a small amount of food. Gastroparesis can occur as a result of several conditions, and is present in 30 percent to 50 percent of patients with diabetes mellitus. A person with diabetic gastroparesis may have episodes of high and low blood sugar levels due to the unpredictable emptying of food from the stomach, leading to diabetic complications. Other causes of gastroparesis include Parkinson's disease and some medications. In many patients the cause cannot be found and the disorder is termed idiopathic gastroparesis.

CYCLIC VOMITING SYNDROME (CVS)

CVS is a disorder with recurrent episodes of severe nausea and vomiting interspersed with symptom free periods. The periods of intense, persistent nausea and vomiting, accompanied by abdominal pain, prostration, and lethargy, last hours to days. Previously thought to occur primarily in pediatric populations, it is increasingly understood that this crippling syndrome can occur in many age groups, including adults. CVS patients often go for years without correct diagnosis. CVS leads to significant time lost from school and from work, as well as substantial medical morbidity. The cause of CVS is not known. Research is needed to help identify at-risk individuals and develop more effective treatment strategies.

SUPPORT FOR CRITICAL RESEARCH

IFFGD urges Congress to fund the NIH at level of \$32 billion for fiscal year 2014.—Strengthening and preserving our Nation's biomedical research enterprise fosters economic growth and supports innovations that enhance the health and well-being of the Nation. Concurrent with overall NIH funding, IFFGD supports the growth of research activities on FGIMDs to strengthen the medical knowledge base and improve treatment, particularly through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Such support would expedite the implementation of recommendations from the NCDD. It is also vital for NIDDK to work with the National Institute of Child Health and Human Development (NICHD) to expand its research on the impact FGIMDs have on pediatric populations. Following

years of near level-funding, research has been negatively impacted across all NIH Institutes and Centers. Without additional funding, medical researchers run the risk of losing promising research opportunities that could benefit patients.

We applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposing hold the potential to speed new treatment to patients. We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2014.

Thank you for the opportunity to present these views on behalf of the FGIMD community.

PREPARED STATEMENT OF THE INTERSTITIAL CYSTITIS ASSOCIATION
SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014

- \$660,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention.
 - \$32 billion for the National Institutes of Health (NIH) and Proportional Increases Across All Institutes and Centers.
 - Support for NIH Research on IC, including:
 - The Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network.
 - Research on IC in Children.
-

Thank you for the opportunity to present the views of the Interstitial Cystitis Association (ICA) regarding the importance of interstitial cystitis (IC) public awareness and research.

ICA was founded in 1984 and remains the only nonprofit organization dedicated to improving the lives of those affected by IC. The Association provides an important avenue for advocacy, research, and education relating to this painful condition. Since its founding, ICA has acted as a voice for those living with IC, enabling support groups and empowering patients. ICA advocates for the expansion of the IC knowledge-base and the development of new treatments, including investigator initiated research. Finally, ICA works to educate patients, healthcare providers, and the public at large about IC.

IC is a condition that consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region. It is often associated with urinary frequency and urgency. This condition may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). It is estimated that as many as 12 million Americans have IC symptoms. Approximately two-thirds of these patients are women, though this condition does severely impact the lives of as many as 4 million men as well. IC has been seen in children and many adults with IC report having experienced urinary problems during childhood. However, little is known about IC in children, and information on statistics, diagnostic tools and treatments specific to children with IC are limited.

The exact cause of IC is unknown and there are few treatment options available. There is no diagnostic test for IC and diagnosis is made only after excluding other urinary/bladder conditions. It is not uncommon for patients to experience one or more years delay between the onset of symptoms and a diagnosis of IC. This is exacerbated when healthcare providers are not properly educated about IC and some patients suffer many years before they are diagnosed and empowered to attempt potential therapies.

The effects of IC are pervasive and insidious, damaging work life, psychological well-being, personal relationships, and general health. The impact of IC on quality of life is equally as severe as rheumatoid arthritis and end-stage renal disease. Health-related quality of life in women with IC is worse than in women with endometriosis, vulvodynia, and overactive bladder. IC patients have significantly more sleep dysfunction, and higher rates of depression, anxiety, and sexual dysfunction.

Some studies suggest that certain conditions occur more commonly in people with IC than in the general population. These conditions include allergies, irritable bowel syndrome, endometriosis, vulvodynia, fibromyalgia, and migraine headaches. Chronic fatigue syndrome, pelvic floor dysfunction, and Sjogren's syndrome have also been reported.

IC PUBLIC AWARENESS AND EDUCATION

The IC Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) is critical to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options.

The IC program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the Internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The CDC IC Education and Awareness Program also provides patient support that empowers patients to self-advocate for their care. Many physicians are hesitant to treat IC patients because of the time it takes to treat the condition and the lack of answers available. Further, IC patients may try numerous potential therapies, including alternative and complementary medicine, before finding an approach that works for them. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life.

ICA recommends continued support for the CDC IC Education and Awareness Program and a specific appropriation of \$660,000 for fiscal year 2014. ICA also encourages continued support for the National Center for Chronic Disease Prevention and Health Promotion which administers the IC program.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

The National Institutes of Health (NIH) maintains a robust research portfolio on IC. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is the primary Institute for IC research. Major studies that have yielded significant new information include the RAND IC Epidemiology (RICE) studies which found that nearly 2.7–6.7 percent of adult women and 2 to 4 million men have symptoms consistent with IC. The IC Genetic Twin study found environmental factors, rather than genetic factors, to be substantial risk factors for developing IC. The Events Preceding Interstitial Cystitis (EPIC) study linked non-bladder conditions and infectious agents to the development of IC in many newly-diagnosed IC patients. The findings of the EPIC study have been reinforced by a Northwestern University study which found that an unusual form of toxic bacterial molecule (LPS) impacts the development of IC as a result of an infectious agent. Finally, the Urologic Pelvic Pain Collaborative Research Network (UPPCRN) indicated promising results for a new therapy for IC patients.

Research currently underway also holds great promise to improving our understanding of IC and developing better treatments and a cure. The NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network studies the underlying causes of chronic urological pain syndromes. The Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health established by the Office of Research on Women's Health (ORWH) includes an IC component. Research on chronic pelvic pain is supported by the National Institute of Neurological Disorders and Stroke (NINDS) as well as the National Center for Complementary and Alternative Medicine (NCCAM). Additionally, the NIH investigator-initiated research portfolio continues to be an important mechanism for IC researchers to create new avenues for interdisciplinary research.

ICA also supports the National Center for Advancing Translational Sciences (NCATS), including the Cures Acceleration Network (CAN). Initiatives like CAN are critical to overhauling the translational research process and overcoming the research "valley of death" that currently plagues treatment development. In addition, drug repurposing and other efforts led by NCATS hold the potential to speed access to new treatment for patients. ICA encourages support for NCATS and the provision of adequate resources for the Center in fiscal year 2014.

ICA recommends a funding level of \$32 billion for NIH in fiscal year 2014. ICA also recommends continued support the MAPP study administered by NIDDK, and the expansion of research focused on IC in children.

Thank you for the opportunity to present the views of the interstitial cystitis community.

PREPARED STATEMENT OF THE JOINT ADVOCACY COALITION (JAC)

JAC Fiscal Year 2014 LHHS Appropriations Recommendations

- Protect clinical and translational research and research training programs from devastating funding cuts due to sequestration and deficit reduction initiatives.
- Provide \$32 billion for NIH, an increase of \$1.3 billion over fiscal year 2012.
- Provide \$434 million for AHRQ, an increase of \$29 million over fiscal year 2012, and meaningful funding increases for related agencies that support patient-centered and comparative effectiveness research.
- Provide \$7 billion for the Health Resources and Services Administration (HRSA), an increase of \$789 million from fiscal year 2012, and meaningful funding increase for related agencies that support clinical and translational research, including research into the health system and healthcare delivery.
- Provide continued support for Federal research training and career development activities such as the “K” and “T” awards programs.

Chairman Harkin, Ranking Member Moran, and distinguished members of the subcommittee, thank you for the opportunity to submit written testimony on behalf of JAC.

The JAC

JAC is comprised of organizations representing the clinical and translational research and research training community, and is led by the Association for Clinical and Translational Science and Clinical Research Forum. These organizations are dedicated to improving the health of the public through clinical and translational research and to supporting this Nation’s research training and career development pipeline. JAC speaks with one voice on behalf of this community to advocate for adequate funding of clinical and translational research and research training programs at NIH, AHRQ, and related Federal agencies, and the Patient-Centered Outcomes Research Institute (PCORI).

Deficit Reduction and Sequestration

Our Nation’s investment in the full spectrum of biomedical research from molecules to populations is an engine that drives economic growth while improving health outcomes for patients with chronic, costly, and life-threatening conditions. Research projects funded through NIH, AHRQ, HRSA, and related agencies are conducted at academic health centers, community hospitals, and other local settings across the country. Federally-supported clinical and translational research activities have a major economic impact on local communities, which includes high-quality job creation, in addition to forming a cornerstone of this Nation’s biotechnology industry. Translational research embraces and connects the two poles of biomedical research, from bench to bedside and from clinical trials to broad application in the population. Cutting funding to NIH, AHRQ, HRSA, and related programs would have direct and immediate negative consequences for the local communities that support clinical and translational research activities.

Equally troubling and problematic is the message that funding cuts to biomedical research send to the next generation of young scientists. Medical research activities are not a faucet that can simply be turned off and on with funding. When funding begins to dry up, our best and brightest are faced with a strong disincentive to pursue a career in this field. It is difficult to justify a long and demanding period of training when a young investigator has slim chances of securing a Federal grant to support their research. Currently, NIH cannot fund many promising meritorious grant submissions and only funds less than 10 percent of all grant applications. Further, the average age for a researcher to receive their first grant is presently 42. If funding is cut further, the “pay line” at which funding is possible will continue to drop and the average age for securing a grant will rise. Compounding this situation is a very real threat to losing top research talent posed by biotechnology investments being made by several other countries. China alone plans to dedicate \$300 billion to medical research over the next 5 years; this amount is double the current NIH budget over the same period of time. Research is not beholden to language or culture and young investigators will gravitate towards any country that has the resources to support their promising research. Unless we provide a meaningful investment in clinical and translational research training programs over the coming years, our loss will be our competitors’ gain. We will concede innovation in healthcare delivery and cutting-edge therapies to foreign biotech industries.

Most importantly, cutting funding to clinical and translational research programs will delay and jeopardize healthcare advances that would benefit patients dealing with serious and life-threatening medical conditions and cut healthcare costs. Research leading to new therapies and how these new therapies can be used in evi-

dence-based medical care is essential to controlling healthcare costs. Prevention through interventions like new vaccines has been demonstrated to save healthcare costs. Federal programs focused on developing personalized medicine and patient-focused care are only just beginning to be implemented. If these programs are forced to confront reduced resources in their infancy, they may never be able to achieve their potential or accomplish their missions. A loss of funding for NIH, AHRQ, HRSA, and related agencies would seriously undermine the ongoing effort to bring this country's healthcare system into the 21st century. Setbacks in this area would be felt by members of every community; since neither industry nor hospitals support these critical components of research that lead to new drugs, vaccines, devices, and diagnostics.

Support for Clinical and Translational Research Activities

With the establishment of the Clinical and Translational Science Awards (CTSA) program in 2006, NIH began a commitment to supporting the full spectrum of research to bridge the "valley of death" between basic scientific discoveries and bedside therapies, diagnostic tools, and practices. In 2011, the CTSA Consortium reached its planned size of approximately 60 medical research institutions located in 30 States throughout the Nation, linking them together to energize the discipline of clinical and translational science. The CTSA's have an explicit goal of improving healthcare in the United States by transforming the biomedical research enterprise to become more effectively translational.

Although the promise of the CTSA program is recognized both nationally and internationally, it has suffered from a lack of adequate funding. In 2006, 16 initial CTSA's were funded, followed by 12 in 2007, 14 in 2008, 4 in 2009, 9 in 2010, and 5 in 2011. Level funding at NIH curtailed the growth of the CTSA's, preventing institutions from fully implementing their awards and causing them to drastically alter their budgets after research had already begun. As a testament to the strength of the concept, the CTSA program continues to generate significant scientific progress with limited resources. With full funding, the CTSA program could be even more successful and productive. While the Nation could benefit from additional CTSA's in the future, the current sites are having an enormous impact, so any attempt to provide full funding should not curtail the current number of sites or limit the geographic diversity of the program.

Prevention science and comparative effectiveness research (CER) are new approaches to evaluate the impact of different options that are available for preventing or treating a given medical condition for a particular set of patients. These can include medications, lifestyle therapies, and medical devices, among other interventions. Both AHRQ and NIH have long histories of supporting CER and prevention research, and the standards for research instituted by these agencies serve as models for best practices worldwide. Not only are these agencies experienced in CER, they are universally recognized as impartial and honest brokers of information. Moreover, their approach enables and does not duplicate the approach of PCORI. Continued support is critical to ensuring that patients benefit from the best information for them and their doctors to make healthcare decisions.

Support for Research Training and Career Development Programs

The future of our Nation's biomedical research enterprise relies heavily on the maintenance and continued recruitment of promising young investigators. The "T" and "K" series awards at NIH and AHRQ provide much-needed support for the career development of young investigators. These programs are efficient because they provide training to small groups and not individual trainees. As clinical and translational medicine takes on increasing importance, there is a great need to grow these programs, not to reduce them. Career development grants are crucial to the recruitment of promising young investigators, as well as to the continuing education of established investigators. Reduced commitment to the K-12, K-23, K-24, and K-30 awards would have a devastating impact on our pool of highly trained clinical researchers. Even with the full implementation of the CTSA program, it is critical for institutions without CTSA's to retain their K-30 Clinical Research Curriculum Awards, as the K-30s remain a highly cost-effective method of ensuring quality clinical research training. The JAC urges you to support the ongoing commitment to research training through adequate funding for T and K series awards.

Thank you for the opportunity to present the views and recommendations of the clinical research training community. Please contact JAC if you have any questions or if you would like any additional information.

PREPARED STATEMENT OF THE LUNG CANCER ALLIANCE

Lung Cancer Alliance is grateful for the opportunity to share our views on the pending fiscal year 2014 Appropriations and the potential impact on the operation of the U.S. Preventive Services Task Force (USPSTF) and the Agency for Healthcare Research and Quality (AHRQ) within the Department of Health and Human Services (HHS).

Lung Cancer is the leading cause of cancer death in the United States. Nearly one third of all cancer deaths in the U.S. are lung cancer deaths. Each year, 160,000 lives are lost to lung cancer. Sixty percent of the people diagnosed with lung cancer today are former smokers who heeded the call to quit. Over 75 percent of lung cancers are diagnosed at late stage when treatment options are limited, expensive and sadly, often futile. This can change.

In November 2010, the National Cancer Institute (NCI) announced it was terminating the largest, most expensive randomized control trial in its history because the trial demonstrated conclusively—sooner than expected—that screening those at high risk for lung cancer with CT scans could greatly reduce lung cancer deaths. The National Lung Screening Trial (NLST) compared low dose CT screening to x-rays for the detection of lung cancer in people over 55 with a significant smoking history and found that low dose CT screening provided a 20 percent mortality benefit. To put this into context, the overall mortality benefit for mammography is 15 percent. These are substantial mortality benefits and for a cancer as widespread and impactful as lung cancer, it means that tens of thousands of lives could be saved each year if lung cancer screening is deployed responsibly and equitably.

Despite this conclusive scientific evidence and subsequent published and peer reviewed studies that show low dose CT screening is cost effective from a commercial payers perspective, to date, USPSTF has failed to make a recommendation. This failure to make a recommendation has literally been the difference between life and death for those who continue to be diagnosed for lung cancer at late stage.

We have profound concerns about the operation of the U.S. Preventive Services Task Force in this era of expanded authority under the Affordable Care Act (ACA). Because of the ACA, USPSTF now not only determines what benefits will be covered by Medicare and Medicaid but also what services will be considered an Essential Health Benefit for coverage in State and Federal health care exchanges. Preventive Services receiving less than an A or B recommendation are not required to be covered by the commercial health plans offered through these exchanges.

The ACA is replete with references to transparency in the operation of exchanges and other provisions, but silent in this regard with respect to USPSTF. Initially, and in anticipation of an escalation in the number of concerns already being expressed by some members of Congress, USPSTF announced in 2011 a new initiative to “make its recommendations clearer and its processes more transparent.”

With lung cancer screening under review at the time, Lung Cancer Alliance was asked to participate in the pilot project, which included the first “Topic Groups for Stakeholders” (TOPS), a key component of the new openness that USPSTF described as an effort to make its work “more transparent and trustworthy.” As you can imagine, Lung Cancer Alliance immediately agreed to participate. Unfortunately, since that first and only call on November 10, 2011, there has been no additional actions or activities. Despite repeated requests, Lung Cancer Alliance has not been given any information regarding the other members of the lung cancer TOPS, the final research plan, the reviewers who were selected, how they were selected or the timeline for draft recommendations. We have not even been told who else was on the one TOPS call.

While the lack of transparency is deeply disappointing and inexplicable, the lethargic pace of USPSTF in reviewing CT screening is having tragic consequences in lives lost. On average, 435 people a day die of lung cancer. If screening is implemented right and well, 200 people a day could be saved. Thus, tens of thousands of lives a year are at stake. Studies by Milliman Inc. have also validated its cost efficiency.

Yet, as it now stands, since lung cancer screening has not yet received an A or B recommendation, CT lung cancer screening for those at high risk will not be covered under Medicare, Medicaid or included as an Essential Health Benefit for insurance purchased through the exchanges.

For many of those at high risk, unless action is taken by Congress, this unfortunate convergence of bureaucratic delays and the arbitrary deadline in inclusion under the Affordable Care Act will be a de facto of denial of access to this life saving, cost efficient benefit.

We urge the Committee to direct the Secretary of Health and Human Services to include CT screening of those at high risk for lung cancer as an Essential Health Benefit and as a covered benefit under Medicare and Medicaid.

PREPARED STATEMENT OF THE MARCH OF DIMES FOUNDATION

MARCH OF DIMES: FISCAL YEAR 2014 FEDERAL FUNDING PRIORITIES
[Dollars in thousands]

Program	Fiscal Year 2014 Request
National Institutes of Health (Total)	32,000,000
National Children's Study	192,000
Common Fund	570,530
National Institute of Child Health and Development	1,370,000
National Human Genome Research Institute	536,967
National Institute on Minority Health and Disparities	289,426
Centers for Disease Control and Prevention (Total)	7,800,000
National Center for Birth Defects and Developmental Disabilities	139,000
Birth Defects Research and Surveillance	22,300
Folic Acid Campaign	2,800
Section 317	720,000
Polio Eradication	126,400
Safe Motherhood Initiative	44,000
Preterm Birth	2,000
National Center for Health Statistics	162,000
Health Resources and Services Administration (Total)	7,000,000
Title V, Maternal and Child Health Block Grant	640,000
SPRANS—Infant Mortality and Preterm Birth	3,000
Heritable Disorders	13,300
Universal Newborn Hearing	18,660
Community Health Centers	1,580,000
Healthy Start	103,532
Children's Graduate Medical Education	317,500
Agency for Healthcare Research and Quality (Total)	430,000

The three million volunteers and 1,200 staff members of the March of Dimes Foundation appreciate the opportunity to submit Federal funding recommendations for fiscal year 2014 (fiscal year 2014). The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the business community and other volunteers affiliated with 51 chapters and 213 divisions in every State, the District of Columbia and Puerto Rico. The March of Dimes recommends the following funding levels for programs and initiatives that are essential investments in maternal and child health.

Preterm Birth

Preterm birth is a serious health problem that costs the United States more than \$26 billion annually. Employers, private insurers and individuals bear approximately half of the costs of health care for these infants, and another 40 percent is paid by Medicaid. One in nine infants in the U.S. is born preterm. Prematurity is the leading cause of newborn mortality and the second leading cause of infant mortality. Among those who survive, one in five faces health problems that persist for life such as cerebral palsy, intellectual disabilities, chronic lung disease, and deafness. In 2011, the Nation's preterm birth dropped for the fifth consecutive year to 11.7 percent, giving thousands more infants a healthy start in life and saving billions in health and social costs. We believe one of the factors behind the decline was Congress's passage of the 2006 PREEMIE Act (Public Law 109-450), which brought the first-ever national focus to prematurity prevention. The Surgeon General's Conference on the Prevention of Preterm Birth created by the Act generated a public-private agenda to spur innovative research at the National Institutes of Health

(NIH) and Centers for Disease Control and Prevention (CDC) and advanced evidence-based interventions to prevent preterm birth. The March of Dimes' fiscal year 2014 funding requests regarding preterm birth are based on the recommendations from 2008 conference and the PREEMIE Act.

National Children's Study (NCS)

The March of Dimes recommends \$192 million in fiscal year 2014 for the National Children's Study to allow for roll-out of the main study with a science-based design and recruitment strategy. The NCS is the largest and most comprehensive study of children's health and development ever planned in the U.S. When fully implemented, this study will follow 100,000 children in the U.S. from before birth until age 21. The data has the potential to transform our understanding of child health and development, and to lead to new forms of prevention and treatment for a multitude of conditions and diseases of childhood.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

The March of Dimes recommends at least \$1,370 million for the NICHD in fiscal year 2014. This funding will allow NICHD to sustain its preterm birth-related research through extramural grants, Maternal-Fetal Medicine Units, the Neonatal Research Network and the intramural research program. This funding would also allow for NICHD to invest in transdisciplinary research to identify the causes of preterm birth, as recommended in the Director's 2012 Scientific Vision for the next decade, the Institute of Medicine 2006 report on preterm birth, and the 2008 Surgeon General's Conference on the Prevention of Preterm Birth. The March of Dimes fully supports NICHD's pursuit of transdisciplinary science, which will facilitate the exchange of scientific ideas and lead to novel approaches to understanding complex health issues and their prevention.

Centers for Disease Control and Prevention—Preterm Birth

The mission of the CDC's National Center for Chronic Disease Prevention and Health Promotion's Safe Motherhood Initiative is to promote optimal reproductive and infant health. The March of Dimes recommends funding of \$44 million for the Safe Motherhood program and re-instatement of the preterm birth sub-line at \$2 million, as authorized in the PREEMIE Act, to reflect current preterm birth research within the CDC.

Health Resources and Services Administration (HRSA)—Preterm Birth

The March of Dimes recommends the subcommittee specify \$3 million within the Title V, Special Projects of Regional and National Significance account be used to support current preterm birth and infant mortality initiatives, as authorized in the PREEMIE Act, and to support the expansion of its initiatives nationwide. The PREEMIE Act authorized preterm birth-related demonstration projects, which are aimed at improving education, treatment and outcomes for babies born preterm. Currently, HRSA is pursuing the Collaborative Improvement & Innovation Network (COIN) to Reduce Infant Mortality, which brings together infant mortality experts to share best practices and lessons learned. Through the COIN, State agencies are focusing on a range of interventions proven to reduce preterm birth and improve maternal and child health, including reducing elective deliveries before 39 weeks and implementing evidence-based smoking cessation initiatives. Expanding the COIN initiative nationwide will reduce preterm birth rates and infant mortality.

Birth Defects

According to the CDC, an estimated 120,000 infants in the U.S. are born with major structural birth defects each year. Birth defects are the leading cause of infant mortality and the causes of more than 70 percent are unknown. Additional Federal resources are sorely needed to support research to discover the causes of all birth defects and for the development of effective interventions to prevent or at least reduce their prevalence.

CDC—National Center on Birth Defects and Developmental Disabilities (NCBDDD)

For fiscal year 2014, the March of Dimes requests funding of \$139 million for NCBDDD. We also encourage the subcommittee to provide at least \$2.8 million to support folic acid education and \$22.3 million to support birth defects research and surveillance—a \$2 million increase from fiscal year 2012 enacted levels. Allocating an additional \$2 million to birth defects research and surveillance will support genetic analysis of the research samples already obtained through the NCBDDD's National Birth Defects Prevention Study—the largest case-controlled study of birth defects ever conducted. Further, allocating at least \$2 million to folic acid education

will allow the CDC to sustain its effective education campaign aimed at reducing the incidence of spina bifida and anencephaly by promoting consumption of folic acid.

Newborn Screening

Newborn screening is a vital public health activity designed to identify genetic, metabolic, hormonal and functional disorders in newborns. Screening detects conditions in newborns that, if left untreated, can cause disability, developmental delays, intellectual disabilities, serious illnesses or even death. If diagnosed early, many of these disorders can be managed successfully. The March of Dimes urges the subcommittee to provide \$13.3 million for HRSA's heritable disorders program and the work of the Advisory Committee on Heritable Disorders in Newborns and Children, as authorized by the Newborn Screening Saves Lives Act (Public Law 110-204). In 2013, the United States will mark the 50th anniversary of newborn screening. The Heritable Disorders program plays a critical role in assisting States in the adoption of additional screenings, enhancing provider and consumer education and ensuring coordinated follow-up care.

Closing

The Foundation's volunteers and staff in every State, the District of Columbia and Puerto Rico look forward to working with Members of this subcommittee to secure the resources needed to improve the health of the Nation's mothers, infants and children.

PREPARED STATEMENT OF THE MEALS ON WHEELS ASSOCIATION OF AMERICA

Thank you for the opportunity to present testimony to your subcommittee concerning fiscal year 2014 funding for Older Americans Act (OAA) Nutrition Programs administered by the Administration for Community Living (ACL)/Administration on Aging (AoA) within the U.S. Department of Health and Human Services (HHS). I am Ellie Hollander, President and CEO of the Meals On Wheels Association of America. As you may know, we are the oldest and largest national organization representing local, community-based Senior Nutrition Programs—both congregate and home-delivered (commonly referred to as Meals on Wheels)—in all 50 States and Territories. As a national organization and network, we are working together to end senior hunger in America by 2020.

Every day, thousands of Senior Nutrition Programs in every State provide nutritious meals and daily social contact to seniors 60 years of age or older who are at significant risk of hunger and losing their ability to remain independent in their own homes and communities. More than 70 percent of the Members of our Association provide both types of meals authorized under the OAA—nutritious meals served in congregate locations such as senior centers, as well those served directly to the residences of homebound seniors. Today, I speak on behalf not only of the national network of Senior Nutrition Programs and for the hundreds of thousands of seniors nationwide who rely on these programs for their primary source of nutritious food. But I also speak for millions of other seniors who need meals but are not able to receive them—not because we lack the infrastructure and expertise to serve them but because there are not adequate financial resources to do so.

One of the great strengths of Senior Nutrition Programs for which we are truly proud, is that they are strong public-private partnerships. Not only do these programs engage volunteers from the community, they raise significant private funds in their communities to augment the limited Federal funds furnished through the annual Labor, Health and Human Services, Education and Related Agencies appropriation bills. Nationally, about 30 percent of the total spending for congregate and home-delivered meals is provided through Older Americans Act funding. The rest must be raised from State and local sources as well as private donations. However, in recent years, it has proven more and more difficult to leverage funding from these other sources. Year after year, Senior Nutrition Programs are serving fewer seniors and meals at a time when the need and demand is growing at an unprecedented pace.

Currently, Senior Nutrition Programs face ongoing challenges, including:

- Sequestration;
- Year-over-year Federal, State and local budget cuts;
- Rising costs for food, transportation and employees;
- Fewer and smaller private donations due to the slow economy;
- Increased demand, as Baby Boomers turn 65 at the rate of 10,000 a day;
- Increased need, with 8.3 million seniors—or 1 in 7—struggling with hunger today.

Data relating to utilization of OAA Senior Nutrition Programs illustrate how these compounding factors have already reduced the number of meals being served. For example, in 2011, OAA Nutrition Programs served 14 million fewer meals as compared to 2010. Despite the increasing need due to demographics and economic conditions, 88,000 fewer seniors were able to be served across the United States in 2011 as compared to the previous year.

Yet another example of these compounding effects is outlined in the President's fiscal year 2014 Budget, which proposes continued funding for OAA Nutrition Programs for another fiscal year at the fiscal year 2012 level. According to ACL's Congressional Budget Justification, the request for OAA Nutrition Programs—\$816 million—is estimated to support the provision of 214 million meals for 2.3 million seniors. This represents nearly a 14 million meal reductions from 2011 and nearly 28 million fewer meals from 2010. In terms of the decreases in the number of individuals able to be served, it is about 100,000 per year—in 2011, 2.5 million seniors were served; and in 2010, that number was 2.6 million.

Clearly, these compounding factors were already causing reductions in meals and the number of seniors served, even before the automatic cuts were ordered on March 1 of this year. While the specific impact of sequestration is not yet quantifiable, it will be devastating to Senior Nutrition Programs, and in turn devastating, perhaps even life threatening to frail older Americans who rely on them as their only source of nutritious food. As a result of sequestration and the aforementioned challenges, Senior Nutrition Programs have been forced to further reduce meals, cut delivery days, and establish waiting lists, leaving so many of our hidden hungry without the nutrition they need to remain healthy and out of more costly healthcare settings, such as hospitals or nursing homes.

Given these facts, we appeal to this subcommittee to provide increases above the President's request for Title III C1 (Congregate Meals), Title III C2 (Home-Delivered Meals) and Nutrition Services Incentive Program (NSIP) of the OAA. We ask this knowing that the fiscal context in which you are working for this fiscal year 2014 appropriation bill is extraordinarily challenging and knowing that providing increases to our programs likely means reducing or eliminating others. However, we believe that investing in OAA Nutrition Programs is not only morally right, but that there is a strong business and economic case that demonstrates that spending on these programs actually helps to save taxpayers' dollars.

Specifically, research released from Brown University in December 2012, demonstrates the positive impact of increased spending on home-delivered meals programs for seniors. The study compared State-level expenditures on OAA programs with the population of "low-care" seniors in nursing homes (i.e., residents of nursing homes that might not need the suite of services that a nursing home provides). According to the analysis from a decade of spending and nursing home resident data, those States that invest more in home-delivered meals to seniors have lower rates of "low-care" seniors in nursing homes. Home-delivered meals emerged as the most significant factor among OAA services that affected State-to-State differences in low-care nursing home population. The research found that for every \$25 per year per older adult above the national average that States spend on home-delivered meals, they could reduce their percentage of low-care nursing home residents by one percentage point compared to the national average. As you know, a 1 percent reduction in Medicare and Medicaid expenditures can result in significant savings.

At a time when Federal and State budgets are looking for ways to reduce costs, the impact of an investment in home-delivered meal programs, such as Meals on Wheels, can reap tremendous benefits for both the seniors that receive them and the communities that often bear the costs of supporting our seniors. Previous studies have suggested that anywhere from 5 to 30 percent of nursing home residents have low-care needs and could perhaps be better served in their homes.

Additionally, the Center for Effective Government (formerly OMB Watch) released a study on April 30, 2013, that demonstrates the potentially devastating impact sequestration could have not only on Meals on Wheels programs and the seniors they serve, but on our Nation's budget. The report estimated that 39,000 seniors nationwide could, as a result of sequestration's reduction in OAA Home-Delivered Nutrition funding, be forced into nursing homes rather than relying on a combination of home care and home-delivered meals. The shift in living arrangements could cost taxpayers an estimated \$489 million per year in increased Medicaid costs.

Providing adequate funds above fiscal year 2012 levels for Senior Nutrition Programs can only be regarded as a strong and demonstrable value proposition. The more local, community-based Senior Nutrition Programs are able to keep seniors well-nourished and in their own homes where they want to be, the less the Federal Government will need to spend on long-term care, on doctor visits, and stays in the hospital funded by Medicare and Medicaid. The return on investment of each tax-

payer dollar spent on OAA Nutrition Programs is high. In fact, a Senior Nutrition Program can provide meals to a senior for a whole year for approximately the same cost of care for just one day in the hospital or six days in a nursing home.

In closing, I would like to thank this subcommittee again for its longstanding support and acknowledge that our Association understands the difficulty of your task in this challenging budget year. As you consider our request, we respectfully ask that you think of Senior Nutrition Programs not simply as one of the hundreds of programs supported through the Labor, Health and Human Services, Education and Related Agencies appropriations bill, but instead as a high-reward investment—morally and economically—and as a means of helping to reduce our Federal spending by avoiding higher Medicare and Medicaid expenditures.

Again, we thank you for the opportunity to present this testimony to you.

PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND ASSOCIATION OF
ACADEMIC HEALTH SCIENCES LIBRARIES

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- Continue the commitment to the National Library of Medicine (NLM) by supporting the President's budget proposal which requests \$382,252,000, and an additional \$8,200,000 from amounts under Section 241 of the Public Health Service Act, for the National Information Center on Health Services Research and Health Care Technology.
 - Continue to support the medical library community's role in NLM's outreach, telemedicine, disaster preparedness, health information technology initiatives, and health care reform implementation.
-

INTRODUCTION

The Medical Library Association (MLA) and Association of Academic Health Sciences Libraries (AAHSL) thank the subcommittee for the opportunity to submit testimony regarding fiscal year 2014 appropriations for the National Library of Medicine (NLM), an agency of the National Institutes of Health (NIH). Working in partnership with the NIH and other Federal agencies, NLM is the key link in the chain that translates biomedical research into practice, making the results of research readily available to all who need it.

NLM Leverages NIH Investments in Biomedical Research

In today's challenging budget environment, we recognize the difficult decisions Congress faces as it seeks to improve our Nation's fiscal stability. We thank the subcommittee for its long-standing commitment to strengthening NLM's budget. While extramural funding comprises the largest portion of funding for institutes within the NIH, some eighty percent of NLM's budget supports intramural services and programs. Intramural funding builds, sustains, and continually augments NLM's suite of more than 200 databases which provide information access to health professionals, researchers, educators, and the public. It also supports all aspects of library operations and programs, including the acquisition, organization, preservation, and dissemination of the world's biomedical literature, no matter the medium.

In fiscal year 2014 and beyond, it is critical to continue augmenting NLM's baseline budget to support expansion of its information resources, services, and programs which collect, organize, and make readily accessible rapidly expanding biomedical knowledge resources and data. NLM maximizes the return on the investment in research conducted by the NIH and other organizations. The Library makes the results of biomedical information more accessible to researchers, clinicians, business innovators, and the public, enabling such data and information to be used more efficiently and effectively to drive innovation and improve health. NLM is a leader in Big Data and plays a critical role in accelerating nationwide deployment of health information technology, including electronic health records (EHRs) by leading the development, maintenance and dissemination of key standards for health data interchange that are now required of certified EHRs. NLM also contributes to Congressional priorities related to drug safety through its efforts to expand its clinical trial registry and results database in response to legislative requirements, and to the Nation's ability to prepare for and respond to disasters.

Growing Demand for NLM's Basic Services

NLM delivers more than a trillion bytes of data to millions of users daily that helps researchers advance scientific discovery and accelerate its translation into new

therapies; provides health practitioners with information that improves medical care and lowers its costs; and gives the public access to resources and tools that promote wellness and disease prevention. Every day, medical librarians across the Nation use NLM services to assist clinicians, students, researchers, and the public in accessing information they need to save lives and improve health. Without NLM, our Nation's medical libraries would be unable to provide the quality information services that our Nation's health professionals, educators, researchers and patients increasingly need.

NLM's data repositories and online integrated services such as GenBank, PubMed, and PubMed Central are revolutionizing medicine and ushering in an era of personalized medicine in which care is based on an individual's unique genetic profile. GenBank is the definitive source of gene sequence information. PubMed, with more than 22 million citations to the biomedical literature, is the world's most heavily used source of bibliographic information. Approximately 760,000 new citations were added in fiscal year 2012, and it was searched more than 2.2 billion times. PubMed Central is NLM's freely accessible digital repository of full-text biomedical journal articles. On a typical weekday more than 700,000 users download 1.4 million full-text articles, including those submitted in compliance with the NIH Public Access Policy.

As the world's largest and most comprehensive medical library, NLM's traditional print and electronic collections continue to steadily increase each year, standing at more than 11.4 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. By selecting, organizing and ensuring permanent access to health sciences information in all formats, NLM ensures the availability of this information for future generations, making it accessible to all Americans, irrespective of geography or ability to pay, and guaranteeing that citizens can make the best, most informed decisions about their healthcare.

Encourage NLM Partnerships

NLM's outreach programs are essential to MLA and AAHSL membership and to the profession. Through the National Network of Libraries of Medicine (NN/LM), with over 6,000 members in communities nationwide, these activities educate medical librarians, health professionals and the general public about NLM's services and train them in the most effective use of these services. The NN/LM promotes educational outreach for public libraries, secondary schools, senior centers and other consumer-based settings, and its emphasis on outreach to underserved populations helps reduce health disparities among large sections of the American public. NLM's "Partners in Information Access" program improves access by local public health officials to information which prevents, identifies and responds to public health threats and ensures every public worker has electronic health information services that protect the public's health.

NLM's MedlinePlus provides consumers with trusted, reliable health information on more than 900 topics in English and Spanish. It has become a top destination for those seeking information on the Internet, attracting nearly 850,000 visitors daily. Other products and services that benefit public health and wellness include the NIH MedlinePlus Magazine and NIH MedlinePlus Salud, available in doctors' offices nationwide, and NLM's MedlinePlus Connect—a utility which enables clinical care organizations to implement specific links from their electronic health records systems to patient education materials in MedlinePlus.

MLA and AAHSL applaud the success of NLM's outreach initiatives, and we look forward to continuing to work with NLM on these programs.

Emergency Preparedness and Response

Through its Disaster Information Management Research Center, NLM collects and organizes disaster-related health information, ensures effective use of libraries and librarians in disaster planning and response, and develops information services to assist responders. NLM responds to specific disasters worldwide with specialized information resources appropriate to the need, including information on bioterrorism, chemical emergencies, fires and wildfires, earthquakes, tornadoes, and pandemic disease outbreaks. MLA and NLM continue to develop the Disaster Information Specialization (DIS) program to build the capacity of librarians and other interested professionals to provide disaster-related health information outreach. Working with libraries and U.S. publishers, NLM's Emergency Access Initiative makes available free full-text articles from hundreds of biomedical journals and reference books for use by medical teams responding to disasters. MLA and AAHSL ask the subcommittee to support NLM's role in this crucial area which ensures continuous access to health information and use of libraries and librarians when disasters occur.

Health Information Technology and Bioinformatics

For more than 40 years, NLM has supported informatics research, training and the application of advanced computing and informatics to biomedical research and healthcare delivery including telemedicine projects. Many of today's biomedical informatics leaders are graduates of NLM-funded informatics research programs at universities nationwide. A number of the country's exemplary electronic and personal health record systems benefit from findings developed with NLM grant support.

The importance of NLM's work in health information technology continues to grow as the Nation moves toward more interoperable health information technology systems. A leader in supporting the development, maintenance, and dissemination of standard clinical terminologies for free nationwide use (e.g., SNOMED), NLM works closely with the Office of the National Coordinator for Health Information Technology to promote the adoption of interoperable electronic records, and has developed tools to make it easier for EHR developers and users to implement accepted health data standards in their systems.

MLA is a nonprofit, educational organization with 4,000 health sciences information individual and institutional members. Founded in 1898, MLA provides lifelong educational opportunities, supports a knowledge base of health information research, and works with a network of partners to promote the importance of quality information for improved health to the health care community and the public.

The Association of Academic Health Sciences Libraries (AAHSL) supports academic health sciences libraries and directors in advancing the patient care, research, education and community service missions of academic health centers through visionary executive leadership and expertise in health information, scholarly communication, and knowledge management.

Thank you again for the opportunity to present our views. We look forward to continuing this dialogue and supporting the subcommittee's efforts to secure the highest possible funding level for NLM in fiscal year 2014 and the years beyond to support the Library's mission and growing responsibilities. Information about NLM and its programs can be found at <http://www.nlm.nih.gov>.

PREPARED STATEMENT OF THE MEHARRY MEDICAL COLLEGE

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

-
- 1) Funding for the Title VII Health Professions Training Programs, including:
 - \$24.602 million for the Minority Centers of Excellence.
 - 2) \$32 billion for the National Institutes of Health and a Proportional Increase for the National Institute on Minority Health and Health Disparities.
 - Proportional funding increase for Research Centers for Minority Institutions.
 - 3) \$65 million for the Department of Health and Human Services' Office of Minority Health.
 - 4) \$65 million for the Department of Education's Strengthening Historically Black Graduate Institutions Program.
-

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you. I am Dr. Wayne J. Riley, President and CEO of Meharry Medical College in Nashville, Tennessee. I have previously served as vice-president and vice dean for health affairs and governmental relations and associate professor of medicine at Baylor College of Medicine in Houston, Texas and as assistant chief of medicine and a practicing general internist at Houston's Ben Taub General Hospital. In all of these roles, I have seen firsthand the importance of minority health professions institutions and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. First, I want to say that it is clear that health disparities among various populations and across economic status are rampant and overwhelming. Over the next 10 years, we will need to be able to deliver more culturally relevant and culturally competent healthcare services. Bringing healthcare delivery up to this higher standard can serve as our Nation's own preventive healthcare agenda keeping us well positioned for the future.

Minority health professional institutions and the Title VII Health Professions Training programs address this critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist

for all of the health professions in our Nation's most medically underserved communities. Our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example, African Americans represent approximately 15 percent of the U.S. population while only 2–3 percent of the Nation's healthcare workforce is African American.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006 (fiscal year 2006) and fiscal year 2007 Funding Resolution passed earlier this Congress. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating.

Mr. Chairman, I feel like I can speak authoritatively on this issue because I received my medical degree from Morehouse School of Medicine, a historically black medical school in Atlanta. I give credit to my career in academia, and my being here today, to Title VII Health Profession Training programs' Faculty Loan Repayment Program. Without that program, I would not be the president of my father's alma mater, Meharry Medical College, another historically black medical school dedicated to eliminating healthcare disparities through education, research and culturally relevant patient care.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of "Hispanic", "Native American" and "Other" Historically black COEs. For fiscal year 2014, I recommend a funding level of \$24.602 million for COEs.

NATIONAL INSTITUTES OF HEALTH (NIH)

National Institute on Minority Health and Health Disparities.—The National Institute on Minority Health and Health Disparities (NIMHD) is charged with addressing the longstanding health status gap between minority and nonminority populations. The NIMHD helps health professional institutions to narrow the health status gap by improving research capabilities through the continued development of faculty, labs, and other learning resources. The NIMHD also supports biomedical research focused on eliminating health disparities and develops a comprehensive plan

for research on minority health at the NIH. Furthermore, the NIMHD provides financial support to health professions institutions that have a history and mission of serving minority and medically underserved communities. For fiscal year 2014, I recommend that this Institute's funding grow proportionally with the funding of the NIH and add additional FTEs.

Research Centers at Minority Institutions.—The Research Centers at Minority Institutions program (RCMI) is now housed at the National Institute on Minority Health and Health Disparities (NIMHD). RCMI has a long and distinguished record of helping our institutions develop the research infrastructure necessary to be leaders in the area of health disparities research. Although NIH has received unprecedented budget increases in recent years, funding for the RCMI program has not increased by the same rate. Therefore, the funding for this important program grow at the same rate as NIH overall in fiscal year 2014.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of Minority Health.—Specific programs at OMH include:

- Assisting medically underserved communities with the greatest need in solving health disparities and attracting and retaining health professionals,
- Assisting minority institutions in acquiring real property to expand their campuses and increase their capacity to train minorities for medical careers,
- Supporting conferences for high school and undergraduate students to interest them in health careers, and
- Supporting cooperative agreements with minority institutions for the purpose of strengthening their capacity to train more minorities in the health professions.

The OMH has the potential to play a critical role in addressing health disparities, but this role can only be fulfilled if this agency continues its grant making authority. For fiscal year 2014, I recommend a funding level of \$65 million for the OMH.

DEPARTMENT OF EDUCATION

Strengthening Historically Black Graduate Institutions Program.—The Department of Education's Strengthening Historically Black Graduate Institutions program (Title III, Part B, Section 326) is extremely important to MMC and other minority serving health professions institutions. The funding from this program is used to enhance educational capabilities, establish and strengthen program development offices, initiate endowment campaigns, and support numerous other institutional development activities. In fiscal year 2014, an appropriation of \$65 million is suggested to continue the vital support that this program provides to historically black graduate institutions.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, Meharry Medical College along with other minority health professions institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. Meharry and other minority health professions schools seek to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity as we have done for 1876.

Thank you, Mr. Chairman, for this opportunity.

PREPARED STATEMENT OF THE MINE SAFETY AND HEALTH ADMINISTRATION

We are writing in opposition to the fiscal year 2014 Budget Request for the Mine Safety and Health Administration (MSHA), which is part of the U.S. Department of Labor. In particular, we urge the subcommittee to reject MSHA's proposed defunding of the Assistance to States grant program pursuant to Section 503(a) of the Mine Safety and Health Act of 1977. Over the past several fiscal years, MSHA's budget request for State grants was approximately \$9 million, which approached the statutorily authorized level of \$10 million, but still did not fully consider inflationary and programmatic increases being experienced by the States. In fiscal year 2014, based on a realignment of priorities, MSHA has chosen to zero out funding for State assistance grants. We urge the subcommittee to restore funding to the statutorily authorized level of \$10 million for State grants so that States are able

to fully and effectively carry out their responsibilities under Sections 502 and 503 of the Act, including the training of our Nation's miners.¹

The Interstate Mining Compact Commission is a multi-State governmental organization that represents the natural resource, environmental protection and mine safety and health interests of its 25 member States. The States are represented by their Governors who serve as Commissioners.

It should be kept in mind that, whereas MSHA over the years has narrowly interpreted Assistance to States grants as meaning "training grants" only, Section 503 was structured to be much broader in scope and to stand as a separate and distinct part of the overall mine safety and health program. In the Conference Report that accompanied passage of the Federal Coal Mine Health and Safety Act of 1969, the conference committee noted that both the House and Senate bills provided for "Federal assistance to coal-producing States in developing and enforcing effective health and safety laws and regulations applicable to mines in the States and to promote Federal-State coordination and cooperation in improving health and safety conditions in the Nation's coal mines." (H.Conf. Report 91-761). The 1977 Amendments to the Mine Safety and Health Act expanded these assistance grants to both coal and metal/non-metal mines and increased the authorization for annual appropriations to \$10 million. The training of miners was only one part of the obligation envisioned by Congress.

IMCC's member States are concerned that without full funding of the State grants program, the federally required training for miners employed throughout the U.S. will greatly suffer. States have struggled to maintain efficient and effective miner training programs in spite of increased numbers of trainees and the incremental costs associated therewith. The situation will likely be further exacerbated by new statutory, regulatory and policy requirements that grow out of the various reports and recommendations attending the Upper Big Branch tragedy. In spite of all this, MSHA has chosen to eliminate funding completely for this critical component of its statutory obligations. In addition to State training programs, these assistance grants also support State mine rescue training programs, mine rescue competitions, EMT training, miner certifications, accident investigations and reporting, review and approval of company safety plans, and, for those States that operate more comprehensive mine safety and health programs (such as PA, WV, VA, OH, IL, AL, KY and OK), program administrative costs such as supplies, staff training, and travel. We can provide a breakdown of these costs at the Committee's request.

In MSHA's budget justification document (at page 68), the agency states that: "Training plays a critical role in preventing deaths, injuries, and illnesses on the job. By providing effective training, miners are able to recognize possible hazards and understand the safe procedures to follow. MSHA will continue its increased visibility and emphasis on training because it is critically important to making progress in reducing the number of injuries and fatalities." Furthermore, in an April 25, 2013 communication to State grant recipients, MSHA specifically stated that "effective and appropriate training will ensure that miners recognize and understand hazards and how to control or eliminate them." In a similar letter dated March 5, 2012, MSHA noted that "the number of miners you reach yearly through the training your program provides makes your contribution to the success of the program all that more important."

We are mystified about how MSHA intends to accomplish these stated objectives without the training and other programs that are provided by the States pursuant to the grants they receive from MSHA—as has been the case since the enactment of the Mine Safety and Health Act in 1969. By way of an explanation for the drastic cut to State grants, MSHA indicates on page 69 of its budget justification document that the agency has "shifted priorities towards strengthening its enforcement programs. The fiscal year 2014 request prioritizes activities MSHA performs and applies limited budgetary resources to those areas where they will have the greatest impact." MSHA goes on to note that it "considers effective enforcement a top priority and proactive strategy to ensure workplaces in the mining industry are safe and healthy". And yet, in recent fatality and accident investigation reports, MSHA has noted that the majority of these occurrences were due to ineffective training (generally by mine operators) and could have been prevented if more had been done to educate miners about the dangers associated with mining operations and conditions. See <http://www.msha.gov/fatals/fabm2013.asp>.

¹ We should also note that to date, the States have still not received official notification from MSHA about grant awards for fiscal year 2013. Until that occurs, States will be unable to submit grant applications as anticipated by Section 503 of the Act. In this regard, we would also note that MSHA has inappropriately, and likely illegally, expanded the across-the-board cuts required by sequestration from 9 percent to 65 percent without justification or authorization.

MSHA's suggested fix for the de-funding of the State grant program is to immediately shift training responsibilities and costs entirely to mine operators. While this idea may have merit, we are uncertain about the ability of the mining industry (especially small operators) to accommodate these new costs and suspect that any realignment of training responsibilities from the States to the industry will take considerable time and planning. Furthermore, our experience over the past 35 years has demonstrated that the States are often in the best position to design and offer this training in a way that insures that the goals and objectives of Sections 502 and 503 of the Mine Safety and Health Act are adequately met. There is some evidence of training programs offered by mine operators (or contractors on their behalf) falling well below what would be considered a minimum standard for these types of programs.

There have been no discussions with the States about the impacts that this proposal will have on State training programs or mine safety and health programs or about any sort of transition in how we are currently doing business. To propose such a dramatic shift without first consulting the States is inappropriate and a denigration of the role the States have played in protecting our Nation's miners. Furthermore, to expect such a drastic change in operations to occur within a single fiscal year is unrealistic and will only result in confusion and potential negative impacts to the availability and quality of miner training and the overall health and safety of miners.

MSHA notes in its budget justification document that the de-funding of State training grants will result in 180,000 miners in 47 States and the Navajo Nation not receiving training compared to results in fiscal year 2012. Those figures we believe are under-reported and fail to reflect the full impact that the elimination of this funding will have on the States. Examples of the direct impacts being reported by just some of the IMCC member States as a result of MSHA's decision follow. More expanded information from each State is appended to this statement and we request that it be included in the record. The most recent accounting of the number of miners trained by the States (and whose training could be jeopardized by funding cuts) is as follows:

- Kentucky*: Trained or tested over 10,000 people from 10/01/12–03/30/13.
- Louisiana*: 1,000 miners trained.
- Alaska*: 2,600 miners trained.
- New Mexico*: 2,000+ miners trained.
- Oklahoma*: 5,000 miners trained.
- Pennsylvania*: 7,000 miners trained.
- Ohio*: 2,600 miners trained (including for mine rescue).
- Colorado*: 2,800–3,700 miners trained.
- Arkansas*: 2,000 miners trained
- North Carolina*: 6,000–8,000 miners trained.

Interestingly, while MSHA is proposing to eliminate funding for State training grants, it is proposing to increase funding by \$800,000 and 6 FTEs for its Educational Field Services training specialists to "review training plans, monitor and assist industry instructors to develop and improve their skills, and assist mine operators with their health and safety program." From our perspective, this reflects an acknowledgement on MSHA's part that the transition to a totally industry-lead training initiative will likely be fraught with difficulties. However, heavy-handed Federal oversight is not the solution to an effective training program. We have seen this type of approach fail in the past and assert that the training programs operated by the States have resulted in a higher level of success, as indicated by the significantly reduced rates of injuries and fatalities over the past several years. Congress has clearly understood this dynamic as well, appropriating the necessary moneys needed to preserve and enhance State training programs. It should also be kept in mind that effective training programs operated by the States, especially for small operators, are the first and best method to reduce accidents, injuries and fatalities in mines. On the other hand, enforcement often comes too late to be effective, and by its very nature is not preventative. We are hopeful that Congress will once again recognize these operational realities in fiscal year 2014 and turn back MSHA's efforts to undercut these valuable programs.

While we can appreciate MSHA's desire to realign its resources to focus on inspection and enforcement, one of the most effective ways to insure miner health and safety in the first place is through comprehensive and excellent training. MSHA Assistant Secretary Main specifically spoke to this in the letter he sent to State grant recipients last year wherein he stated: "As in the past, we are reaching out to the grantees, recognizing the positive impact you have in delivering training to miners. I am asking that you incorporate, as appropriate, training on these types of [fatal] accidents as well as measures needed to prevent them. Increased training and

awareness is necessary if we are to prevent these types of deaths.” The States have been in the forefront of providing this training for over 35 years and are best positioned to continue that work into the future. Furthermore, the Federal Government’s relatively modest investment of money in supporting the States to handle this training has paid huge dividends in protecting lives and preventing injuries. The States are also able to provide these services at a cost well below what it would cost the Federal Government to do so.

As you consider our request to reject MSHA’s proposed cut and instead to increase MSHA’s budget for State assistance grants, please keep in mind that the States play a particularly critical role in providing special assistance to small mine operators (those coal mine operators who employ 50 or fewer miners or 20 or fewer miners in the metal/nonmetal area) in meeting their required training needs. This has been a particular focus in those States where metal/non-metal mining operations predominate. These are often small business operators who cannot afford to offer the comprehensive training that is required under Section 502 of the Mine Safety and Health Act. Given this Administration’s articulated concerns about the impacts of regulatory decisions on small businesses, it is surprising that MSHA would propose significant cuts to the training that States provide to these small operators. Some States have also recently received requests from the VFW to provide “new miner training” for returning war veterans in order to prepare them for potential employment in the mining industry. Without the funding provided to States by MSHA, this may be difficult to accomplish in a timely manner, if at all.²

We appreciate the opportunity to submit our views on MSHA’s fiscal year 2014 budget request. Please contact us for additional information or to answer any questions you may have.

State Reports re Impacts From De-Funding of Assistance to States Grants Program

In preparation for IMCC’s presentation of this statement to the House and Senate Appropriations Committees, IMCC asked the States three questions, noted below. Responses from each of the reporting States are indicated.

What do you anticipate the impacts to your State will be from the elimination of grant funding, including the number of miners who may not be trained?

- Kentucky:* These cuts will have a devastating effect on our program. Kentucky trains over 20,000 miners yearly. The money we get from MSHA pays our instructors’ salaries.
- Louisiana:* In Louisiana, the State training is performed through the Louisiana Technical Community College system. If the grant is eliminated, their mine safety training program would be completely eliminated, closing its doors on Sept 30, 2013, and laying off both of its employees. The program trains at least 1,000 miners each year (886 miners from Oct 1, 2012 to present).
- Alaska:* Eliminating MSHA training funding potentially impacts each of the 16,400 employees and thousands of owner/operators and contractors working in Alaska’s mining industry as of January 2013. Up to 2,600 students are MSHA trained and certified each year by the University of Alaska Mine and Petroleum Training Service (“MAPTS”). MAPTS is the MSHA training grant recipient in Alaska.
- New Mexico:* In prior years the State of New Mexico, through New Mexico Institute of Mining and Technology, received \$147,000 from MSHA that was used to train miners in NM to meet the regulatory requirements of 30 CFR Parts 46 and 48 which are mandated training requirements for miners. We train over 2,000 miners in NM yearly. Most of these miners are employed at small business operations in our State that cannot afford trainers at their small operations. In addition we provide Spanish language training to 200–300 miners yearly and are the only service available to Spanish-speaking miners in the State.
- Oklahoma:* The Oklahoma Miner Training Institute (OMTI) is funded in part with the State grant. Utilizing the funding provided, OMTI trains 5,000 miners annually in a variety of courses, such as New Miner and Annual Refresher, in accordance with 30 CFR Parts 46 and 48. Without the fully funded support that the State grant provides, the mining community in Oklahoma will be impacted.
- Pennsylvania:* Pennsylvania trains approximately 7,000 miners and contractors in the Anthracite, Bituminous and Industrial Minerals mines and facilities of

²We are also concerned about proposed cuts for the National Mine Safety and Health Academy, which has traditionally provided State grant recipients access to training programs and lodging without charge. MSHA has proposed a \$1.5 million cut for the Academy that could well eliminate this critical service to the States.

the Commonwealth. This training is provided at no cost to the mining community by in-house staff, Pennsylvania State University and Schuylkill Vo-Tech. We also provide a mine rescue program for small coal and industrial minerals mines to comply with Federal mine rescue requirements and required EMT training through Indiana University of PA at no cost to mine operators. Although a majority of large operators provide training for their employees to meet Federal requirements, small mine and facility operators and contractors rely on the MSHA grant for their training needs. Pennsylvania also relies on the MSHA grant to fund other aspects of our mine safety program. These include staff training, health and safety conferences, mine rescue contests, safety equipment, mine rescue supplies, and travel related to these functions.

—*Ohio*: After reviewing our total surface training numbers for the year 2012, it would appear that 1,369 trainees would not have been trained if not for receiving funding from the States Grant program.

—*Colorado*: The impact of the elimination of the MSHA training grant to the miners of Colorado and our training program will be acute. We trained 5,742 in fiscal year 2011 and 4,316 in fiscal year 2012. This includes, coal, metal, non-metal and contractors who serve the industry. The reduction would be 2,800—3,700 miners not trained, including many that receive training in Spanish. The reduction would be salaries and operating costs for two trainers. (The program has 5 FTE total).

—*Arkansas*: While it is difficult for a service provider to estimate the total impact on our State from the elimination of grant funding, we can address how it will impact our ability to provide the mandatory training to the miners and contractors who have utilized our services for years. While the Arkansas MSHA State Training Program has been proactive in trying to maintain the program and continuing to provide effective training to those requesting our service, it has become increasingly difficult to recover the cost for salaries, State match and travel for the sufficient number of staff needed to meet the demand, as well as the costs for maintaining training equipment and supplies. We have already eliminated one part-time position and raised our training fees, but feel confident that if we have to raise them again to generate the revenue needed to sustain the program, it will become a financial hardship on the small mining operations and contractors who are our primary clients. At the current rate, without raising fees, it is likely we would have to eliminate another part-time position, therefore decreasing our ability to provide the mandatory training to our clients requesting the service. Also, grant funds have been used for our staff to attend national and State MSHA conferences and training events. This would have to be completely eliminated. The Arkansas MSHA State Training Program trains an average of 2,000 individual miners and contractors each year. We have been providing new miner, annual refresher, and first aid training.

—*North Carolina*: If State Grant funding is eliminated, we would be reducing our staff of 6 to a staff of 2 based on our State appropriations and the fact we would not be awarded any additional appropriations. I would estimate there would be 6,000 miners we would not be able to provide training for based on previous number of miners and contractors trained. We average training at around 8,000 miners per year. This would be a devastating burden on the small operators who rely on us to assist them with their safety and health programs. Not only will they have to pay a significant amount of money for future training but the quality of training will certainly be a concern. There are many private instructors who do not provide effective, quality training. The mining industry is experiencing the lowest incident rates ever, lowest amount of accidents, and a record low number of fatalities and we feel quality, effective training plays a major role with accident prevention.

To what extent will the mining in your State be able to “develop their own programs or contract these services”? How long do you anticipate this would take?

—*Kentucky*: The majority of our mines involve small mines and have no trainers. The small mines send their employees to our Office of Mine Safety and Licensing to receive quality training free of charge. These miners will have to pay a private instructor and in turn receive inadequate training and in some cases will receive no training at all. We’ve seen many problems in the past with some private instructors not conducting adequate training and they have been reported to the Federal Mine Safety and Health Review Commission for sanctions.

—*Louisiana*: In the absence of our State training program, the mining industry would have to return to “fending for themselves” to train its miners, resulting in an increased cost to industry and possibly lower quality of training for individual miners.

- Alaska*: The majority of mines in Alaska are small operations with less than 10 employees that do not have the resources or capabilities to develop and maintain their own training and certification systems. It is uncertain how long it may take to develop programs or contract MSHA training services. At this point, there are no MSHA training providers other than MAPTS consistently available for small mines in Alaska.
 - Oklahoma*: The training OMTI provides serves all of the mining industry, in particular the smaller mining operations. Without the training courses offered, the smaller mine sites are most susceptible to see increased costs and lack of fully trained miners as required in 30 CFR Parts 46 and 48.
 - Pennsylvania*: Without the MSHA funding, small operators will have to either conduct their own training or use training contractors. Penn State University and Schuylkill Vo-Tech have established a reputation and trust with the operators with a no fee option. If the operators wish to continue this arrangement, a significant cost per student must be absorbed by the operators. The quality of training provided by the PA Bureau of Mine Safety, Pennsylvania State University, Schuylkill Vo-Tech and Indiana University of PA is very high and loss of this program will have a negative impact on miner safety. It will also impact Pennsylvania's ability to maintain its world class mine safety program and ability to support program functions identified above. One example: Federal law requires all mine rescue teams to attend at least two competitions each year, with the States supporting this requirement by holding and supporting these contests. With State budgets shrinking, the ability to support these contests without Federal funding is in jeopardy.
 - Ohio*: From past experience, the larger mining companies could deal with developing their own programs and could contract out these services if needed. The smaller companies and contract miners would be the ones who either would be left out, or would struggle with maintaining their training programs. As far as the time it would take for these companies and contractors to assume total responsibility for complying with MSHA's training law standards, it would take a considerable amount of time.
 - Colorado*: The reduction in support of mine training particularly affects the medium and small operators who make up 95 percent of the mining operations in Colorado. This severely reduces the affect we can all have on preventing accidents and injuries BEFORE they become a major incident. Unfortunately, this will leave many operators with few resources for safety and health and result in an increase in MSHA enforcement inspection time, citations, and most unfortunately, a likely increase in injury and accident rates in our State.
 - Arkansas*: Since the Arkansas MSHA State Training Program places emphasis on assisting small mining operations and contractors, we are aware that most of these companies are neither staffed nor equipped to provide effective training; whereas, the State Grant staff has multiple years of combined training experience. Small companies are at a distinct disadvantage in the area of providing their own training.
 - North Carolina*: Many small operators will not have the resources to develop their own programs adequately. Many of them would not know how to develop lesson plans, outlines, and have the time or resources to prepare a training program. They would have to contract their training out to consultants. Mine safety training was geared to be site-specific and company-specific which is how we prepare for our classes for mining operations. Consultants will use a "canned program" and there are quality control concerns with a canned program. We know of operators who also rely on on-line training and the miners do not like it because there is no interaction or discussion taking place with on-line training. In terms of how long it will take for an operator to implement its own safety and health training program—probably at least a year or longer.
- What other unanticipated consequences from the elimination of State grant funding might there be, particularly with respect to miner safety and health?*
- Kentucky*: In our opinion the miners will be the ones to suffer most. They will have to pay for the classes, they will not get adequate training, and the end result will be an increase in mine fatalities.
 - Louisiana*: It strikes us as particularly unfortunate that MSHA would choose this route of cost savings given that many fatalities are found to have insufficient training as a root cause.
 - Alaska*: Eliminating training funding is expected to lead to an increase in mining accidents and creates an artificial need for increased enforcement on mine sites. Reduced MSHA-supported training will damage the evolution of safety culture improvements in the mining industry. Focusing solely on enforcement

is likely to further deteriorate individual attitudes toward MSHA and voluntary compliance with MSHA requirements.

- New Mexico*: The Mine Act of 1977 was very specific in Sections 502 and 503 regarding the requirement to train miners and to fund State programs to meet the requirements of the Act. We are a small organization that uses our funding wisely to provide low cost training services to small business and non-English speaking miners in our State. We believe this to be an efficient use of these funds to educate our miners, thereby providing good paying jobs in a safer environment.
- Pennsylvania*: There is no question that cutting the State Grant Program goes against the intent of Congress, but more important it will have a negative impact on the health and safety of our Nation's miners. Every MSHA accident investigation report highlights the need for quality training to eliminate and reduce accidents. Not funding the State Grant Program at the maximum amount (\$10,000,000) is misguided and wrong and will impact our ability to see that all workers go home to their families at the end of each work shift.
- Ohio*: For smaller mines and with the contract miners, their safety training would suffer, thus causing a potential increase in mining accidents and serious injuries.
- Colorado*: Like other States, we maintain a unique and trusting relationship with our mine operators and contractors through regular contact, assistance (such as safety audits, etc.) and education and training. We can quickly access and update our mining community regarding the wide range of regulatory requirements, technological improvements in mine safety and sharing of mine health and safety resources. The State program is the gold standard for providing effective and innovative mine health and safety training and training mine employees and contractors to effectively train their own employees.
- Arkansas*: We believe we will see accidents trend upward. The training provided by the Arkansas MSHA State Training Program has proven to have an impact on reduction in accidents; the statistics reveal that the companies who utilize the State services for their training needs have fewer accidents than the companies who have chosen to go another route to obtain their training. Also, company training might not be comprehensive in certain areas, such as miners' statutory rights, including the right to be provided a safe working environment and the right to refuse to perform unsafe tasks. The State Training program provides comprehensive training that supports accident prevention by focusing on eliminating unsafe practices and conditions that contribute to accidents. State training reinforces miner knowledge of safe work behavior and encourages safe work practices, as well as increasing their knowledge in identifying an unsafe work environment as detailed in the Code of Federal Regulations. In addition to training, the State Training staff receives constant e-mails and phone calls regarding safety and health issues. Many of the companies and/or individuals the State Grants staff have worked with over the years are not comfortable going directly to Federal MSHA with questions or concerns; whereas, the State has developed a cooperative relationship that has proven mutually beneficial.
- North Carolina*: Impacts would include not being available to provide special emphasis projects such as mock drills, mine safety and health law seminars, annual mine safety and health State conferences, explosives safety courses, and not being able to properly prepare training programs geared to site-specific needs of mining operations. Training plan assistance will not be provided. Fatalities, accidents, and incident rates will be on the rise because of ineffective training.

PREPARED STATEMENT OF THE NATIONAL ACADEMY OF PUBLIC ADMINISTRATION

Mr. Chairman and members of the subcommittee: My name is Dan G. Blair, President and CEO, and I appreciate this opportunity to offer the written views of the National Academy of Public Administration (the Academy) on issues affecting the fiscal year 2014 appropriations for agencies and programs within the jurisdiction of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies. I am the President and CEO of the National Academy of Public Administration. Chartered by Congress, the Academy is an independent nonprofit organization dedicated to helping leaders address today's most critical and complex challenges. Our organization consists of nearly 800 Fellows—including former cabinet officers, Members of Congress, governors, mayors, and State legislators, as well as distinguished scholars, business executives, and public administrators.

Governing in the 21st century has become increasingly complex. As mandated by our Charter (Public Law 98–257, Sec. 3), the Academy helps public institutions address their most critical challenges through in-depth studies and analyses, advisory services and technical assistance, Congressional testimony, forums and conferences, and online stakeholder engagement. Our Charter permits Congress to request that the Academy conduct work for Federal cabinet departments and agencies. Currently, we are providing such assistance in the following projects:

—*Assessing the STOCK Act's Financial Disclosure Requirement.*—In response to a Congressional mandate, the Academy is conducting an independent review of the impact of providing financial disclosures online for Executive Branch senior career and political appointees and congressional staff. This review is considering a range of issues, including how best to manage the balance between promoting transparency and accountability while protecting privacy and security. The Academy Panel is examining such critical topics as the degree of risk to Federal missions and employees associated with the online disclosure, as well as any harm that has arisen from current online disclosure in the legislative branch.

—*Evaluating the Pension Benefit Guaranty Corporation's Governance Structure.*—Congress has requested that the Academy conduct a review of the current governance structure of the Pension Benefit Guaranty Corporation (PBGC), which provides retirement income protection to millions of Americans. The Academy has formed a five-member Panel of Fellows to lead this study. The Panel will issue recommendations on such key governance issues as the ideal size and composition of the PBGC Board of Directors and the policies necessary to enhance Congressional oversight and Board transparency, as well as to mitigate potential conflicts of interest.

Over the past few years, the Academy has worked with agencies across the Federal Government to help them address critical governance and management challenges. Further examples of congressionally-mandated work include the two following reports that were released in January 2013:

—*Government Printing Office.*—At the request of Congress, the Academy conducted a broad operational review of Government Printing Office (GPO) to update past studies of GPO operations; examine the feasibility of GPO continuing to perform executive branch printing; and identify additional cost saving operational alternatives. The Academy's independent Panel concluded that, in the digital age, ensuring permanent public access to authentic Government information remains a critical Government responsibility. GPO and the rest of the Federal Government must continue to “reboot” to perform this mission successfully in the digital age. The Panel issued fifteen recommendations intended to position the Federal Government for the digital age, strengthen GPO's business model, and further GPO's continuing transformation.

—*Department of Energy.*—The Department of Energy's (DOE) national laboratories have occupied a central place in the landscape of American science for more than 50 years. Congress tasked the Academy to review how DOE oversees its contractor-operated labs, including a review of the performance metrics and systems that DOE uses to evaluate the performance of the labs. While conducting this review, the Academy Panel overseeing this study determined that these management issues must be considered as part of a broader issue about defining and ensuring the future of the lab complex. The Academy's independent Panel issued findings and recommendations regarding the labs as a national asset, how to evaluate the labs, and how to conduct systems-based oversight.

Apart from the traditional management and congressionally-mandated studies, the Academy endeavors to provide a forum for our Fellows to engage in thought leadership efforts and provide practical support to Federal agencies in addressing pressing issues in public administration. For example, we have been working with the Office of Management and Budget to manage the Collaborative Forum, whereby the Academy facilitates discussions, supports participants in the development of pilot ideas and offers its collective knowledge about the intergovernmental system. The Forum draws on State and other stakeholder expertise to generate, develop, and consult on innovations in how States administer federally funded assistance programs. These innovations seek to improve payment accuracy and service delivery, enhance administrative efficiency and reduce barriers to program access. More information on this project can be found on the Forum's website, <http://home.community.collaborativeforumonline.com/>. I believe that such collaborative efforts between Federal, State, local, and private sector stakeholders can improve program delivery and ultimately reduce costs.

Another example of the exercise of the Academy's thought leadership efforts is evidenced in the election transition area. This past year, the Academy and the American Society for Public Administration (ASPA) launched a joint "Memos to National Leaders" project to develop memos to national leaders on how to address the most challenging policy and management challenges facing the Nation. These memos can be found at www.memostoleaders.org and addressed the following topics:

- Strengthening the Federal Budget Process;
- Rationalizing the Intergovernmental System;
- Administrative Leadership;
- Strengthening the Federal Workforce;
- Reorganization of Government;
- Information Technology and Transparency;
- Managing Big Initiatives;
- Next Steps in Improving Performance; and
- Managing Large Task Public-Private Partnerships.

The memos were developed with both a Presidential and Congressional focus, reflecting the joint ownership of problems and solutions for these major challenges.¹

The Academy has also established a "Political Appointee Project" to inform current discussions about improving the presidential appointments process. We hope to serve as an important forum for this discussion. Our website (<http://www.politicalappointeeproject.org/>) contains information on previous related studies, as well as ongoing commentaries on this issue by Academy Fellows and other experts in the field; serves as a repository of profiles of the key management positions in Government; and provides insights to new political executives on the challenge of managing in Government.

In summary, the Academy has a long track record of working across the Federal Government to address critical governance and management challenges. Effectively managing scarce Federal dollars is a goal shared across the aisle. The Academy stands ready to assist the subcommittee in its oversight efforts to enhance and improve agency and program performance.

PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

Chairman Harkin and distinguished members of the subcommittee, as you begin to craft the fiscal year 2014 (fiscal year 2014) Labor-HHS-Education appropriation bill, the members of the National Area Health Education Center-AHEC Organization (NAO) are pleased to submit this statement for the record recommending \$33.142 million in fiscal year 2014 for the AHEC program authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA). This funding level ensures that AHECs can continue to lead the Nation in the recruitment, training and retention of a diverse health workforce for underserved, rural, and urban communities.

The NAO is the professional organization representing AHECs. The AHEC Program has been established for over 40 years and acts as an effective national primary care training network built on committed partnerships of 120 medical schools and 60 nursing and allied health schools. Additionally, 235 AHEC community-based centers operate in 46 States, 4 territories and 250 rural and urban underserved communities alongside tens of thousands of community practitioners affiliated with the AHEC's national clinical training network.

AHEC is one of the Title VII Health Professions Training programs, originally authorized at the same time as the National Health Service Corps (NHSC) to create a complete mechanism to provide primary care providers for Community Health Centers (CHCs) and other direct providers of health care services for underserved areas and populations. The plan envisioned by creators of the legislation was that the CHCs would provide direct service. The NHSC would be the mechanism to fund the education of providers and supply providers for underserved areas through scholarship and loan repayment commitments. The AHEC program would be the mechanism to recruit providers into primary health careers, diversify the workforce, and develop a passion for service to the underserved in these future providers, i.e. Area Health Education Centers are the workforce development, training and education machine for the Nation's health care safety-net programs. The AHEC program is focused on improving the quality, geographic distribution and diversity of

¹These memos are the opinions and views of their respective authors, and are not the opinions of the Academy or ASPA. They can be accessed at <http://www.memostoleaders.org/memos-national-leaders>.

the primary care healthcare workforce and eliminating the disparities in our Nation's healthcare system.

AHECs develop and support the community based training of health professions students, particularly in rural and underserved areas. They recruit a diverse and broad range of students into health careers, and provide continuing education, library and other learning resources that improve the quality of community-based healthcare for underserved populations and areas.

The AHEC program is effective and provides vital services and national infrastructure. Nationwide, over 431,000 students have been introduced to health career opportunities, and over 30,000 mostly minority and disadvantaged high school students received more than 20 hours each of health career exposure. 63,456 health professions students received training at 11,906 underserved clinical and community-based sites, and furthermore; 442,926 health professionals received continuing education in a variety of disciplines including mental health, allied health, and nursing. AHECs perform these education and training services through collaborative partnerships with Community Health Centers (CHCs) and the National Health Service Corps (NHSC), in addition to Rural Health Clinics (RHCs), Critical Access Hospitals, (CAHs), Tribal clinics and Public Health Departments.

Justification for Recommendations

The AHEC network is an economic engine that fuels the recruitment, training, distribution, and retention of a national health workforce. AHEC stands for JOBS.

- Primary Care services improve the health of the population, and therefore increase productivity of the U.S. workforce, while at the same time, contain costs within the U.S. healthcare system. Primary care practitioners are the front-line in prevention of disease, providing cost savings in the United States healthcare system.
- AHECs are critical in the recruitment, training, and retention of the primary care workforce.
- Research has demonstrated that the community-training network is the most effective recruitment tool for the health professions and those who teach remain longer in underserved areas and communities.
- AHECs are in almost every county in the United States.
- With the aging and growing population, the demand for primary care workforce is far outpacing the supply.
- AHECs continue to educate and train current workforce, as well as recruiting and preparing future workforce.
- AHECs foster a national pipeline for community-based health professions education connecting students to careers, professionals to communities, and communities to better health.
- AHECs introduce over 431,000 students to health career opportunities with a special emphasis on recruiting under-represented minority and disadvantaged students who return to their underserved communities due to the fact that AHEC develops and supports community-based interdisciplinary training in underserved areas.
- AHECs facilitate and support health professionals, facilities, and community based organizations in effectively addressing critical local health issues by providing continuing educational services to improve quality of community based care.
- AHECs trained 442,926 Health Professionals in 46 States and 4 territories in 13,842 Health Professions Shortage Areas (HPSAs)—28.4 percent of those trained were physicians, 19 percent were nurses, and 8.1 percent were allied health professionals.
- AHECs provided 3.2 million contact hours of health education programs to over 246,000 active community members.

The AHEC network's outcomes are the backbone of the Nation's community-based health professions training, with a focus on training primary care workforce.

- HRSA has encouraged functional linkage between Bureau of Primary Care and Bureau of Health Professions Programs.
- AHECs have partnerships with over 1,000 Community Health Centers nationally to recruit, train, and retain health professionals who have the cultural and linguistic skills to serve in HRSA designated underserved areas.
- AHECs via a cooperative agreement with HRSA are training 10,000 primary care providers throughout the country to address OIF/OEF/OND Veteran's mental health, substance abuse, traumatic brain injury and post-traumatic stress disorder for those not utilizing the VA system.

PREPARED STATEMENT OF NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

EXECUTIVE SUMMARY

NAEVR requests fiscal year 2014 NIH funding of \$32 billion, which reflects a \$1.38 billion, or 4.5 percent increase, over fiscal year 2012, which consists of biomedical inflation of 2.8 percent plus modest growth. This recommendation reflects the minimum investment necessary to make up for the twenty percent loss in purchasing power over the last decade, as well as the impact of the sequester, which cut 5.1 percent or \$1.6 billion from NIH's \$30.8 fiscal year 2013 billion budget.

NIH, our Nation's biomedical research enterprise, is unique in that:

- Its basic and clinical research has helped to understand the basis of disease, thereby resulting in innovations in healthcare to save and improve lives.
- Its research serves an irreplaceable role the private sector could not duplicate.
- It has been shown through several studies to be a major force in the economic health of communities across the Nation. The latest United for Medical Research report estimates that NIH funding supported more than 432,000 jobs in 2011, directly or indirectly, and generated more than \$62.1 billion in economic activity.

NAEVR requests National Eye Institute (NEI) funding at \$730 million, commensurate with the overall NIH funding increase. The President's budget proposes an fiscal year 2014 NEI funding reduction of \$2.1 million to a level \$699 million which is unacceptable since:

- It cuts 35 competing grants. The \$36 million cut in fiscal year 2013 NEI funding due to the sequester has already translated into a loss of an estimated 90 grants—any one of which holds the promise to save or restore vision.
- The cut jeopardizes NEI's ability to fund new and compelling scientific ideas to advance research, which were identified through its Audacious Goals Initiative.
- Funding at \$699 million is little more than 1 percent of the \$68 billion annual cost of eye disease/vision impairment in the U.S. With the majority of the 78 million Baby Boomers turning 65 years of age this decade and facing the greatest risk of aging eye disease, a cut jeopardizes NEI's ability to meet the vision challenges presented by this "Silver Tsunami."

CONGRESS MUST IMPROVE UPON THE PRESIDENT'S FISCAL YEAR 2014 REQUEST, SINCE IT CUTS NEI FUNDING BY \$2.1 MILLION, OR 0.3 PERCENT BELOW FISCAL YEAR 2012, REDUCING IT BY \$8 MILLION BELOW ITS BASE FISCAL YEAR 2010 LEVEL

Despite the President's request increasing NIH funding by \$471 million, or 1.5 percent, over the fiscal year 2012 level of \$30.6 billion (net of transfers), it proposes to cut NEI by \$2.1 million, or 0.3 percent, below its fiscal year 2012 level of \$701.3 million (net of transfers). Although the cut is primarily driven by an \$8.9 million reduction due to the conclusion of the NEI-sponsored Ocular Complications of AIDS (SOCA) studies which are funded by the NIH Office of AIDS Research, it is still a cut and drives NEI funding in the wrong direction. The President's proposed fiscal year 2014 NEI funding level of \$699 million falls \$8 million below the base fiscal year 2010 level of \$707 million, the highest NEI funding level ever prior to the addition of American Recovery and Reinvestment Act (ARRA) funding.

Most importantly, the President's proposed fiscal year 2014 NEI cut of \$2.1 million comes after the fiscal year 2013 sequester cut of \$36 million. The President's fiscal year 2014 budget would cut 35 competing grants from NEI funding, which follows the sequester's cut of an estimated 90 grants in fiscal year 2013—any one of which may hold the promise to save or restore vision.

NEI is already facing enormous challenges this decade: each day, from 2011 to 2029, 10,000 citizens will turn 65 and be at greatest risk for eye disease; the African American and Hispanic populations are experiencing a disproportionately higher incidence of eye disease; and the epidemic of obesity is significantly increasing the incidence of diabetic retinopathy and diabetic macular edema. In 2009, Congress spoke volumes in passing S. Res. 209 and H. Res. 366, which designated 2010–2020 as The Decade of Vision. With the fiscal year 2014 LHHS spending bill, Congress can act upon its past resolutions regarding vision and assure that NEI is adequately funded to meet these challenges.

NAEVR also requests NEI funding at \$730 million since our Nation's investment in vision health is an investment in overall health. NEI's breakthrough research is a cost-effective investment, since it is leading to treatments and therapies that can ultimately delay, save, and prevent health expenditures, especially those associated with the Medicare and Medicaid programs. It can also increase productivity, help individuals to maintain their independence, and generally improve the quality of

life, especially since vision loss is associated with increased depression and accelerated mortality.

The very health of the vision research community is also at stake with a decrease in NEI funding. Not only will funding for new investigators be at risk, but also that of seasoned investigators, which threatens the continuity of research and the retention of trained staff, while making institutions more reliant on bridge and philanthropic funding. If an institution needs to let staff go, that usually means a highly-trained person is lost to another area of research or an institution in another State, or even another country.

The proposed reduction in NEI funding threatens the United States' leadership in biomedical research in general, and vision research, specifically.

\$730 MILLION FISCAL YEAR 2014 FUNDING ENABLES NEI TO PURSUE AUDACIOUS GOALS
IN VISION RESEARCH

The NEI is in the middle of a novel planning initiative to identify long-term, ten-year goals in vision research. Under the auspices of the National Advisory Eye Council, this expansion of NEI program planning is designed to engage and energize the vision research community and help the NEI establish the most compelling research priorities by identifying one or more "audacious goals." Most recently, NEI hosted 200 representatives from every sector of the vision community, as well as Government scientists and regulators from various disciplines at the NEI's Audacious Goals Development meeting. NIH Director Francis Collins, M.D., Ph.D. was very enthusiastic about this initiative and urged the attendees to have a "bold vision for vision" by describing NEI's long tradition of leading in the biomedical research arena, including:

- identifying more than 500 genes associated with vision loss, which is one-quarter of all genes discovered to date; and
- funding the successful human gene therapy trial for patients with Leber Congenital Amaurosis, in which treated patients have experienced vision improvement.

The meeting's discussion topics were built around the ten winning submissions from a pool of nearly 500 entries selected through NEI's Audacious Goals in Vision Research and Blindness Rehabilitation Challenge, a competition for bold and novel ideas to dramatically advance vision science. These ideas included restoring light sensitivity to the blind through gene-based therapies and visual prosthetics, pinpoint correction of defective genes, and growing healthy tissue from stem cells for ocular tissue transplants. Translating these and other research ideas into safe and effective treatments to save and restore vision requires adequate funding.

As a result of past funding, the NEI has made great strides in determining the genetic basis of age-related macular degeneration (AMD)—the leading cause of blindness and a disease for which very little could be done just a few short years ago. NEI's AMD Gene Consortium, a network of international investigators, has just discovered seven new regions of the human genome—called loci—that are associated with increased risk of AMD. They also confirmed 12 loci already identified in previous studies. These loci implicate a variety of biological functions, including regulation of the immune system, maintenance of cellular structure, growth and permeability of blood vessels, lipid metabolism, and atherosclerosis. By understanding the genetic basis of the disease and underlying disease mechanisms, NEI can develop appropriate diagnostic and therapies.

As an example of NEI-supported research that saves vision, in February 2013 the Food and Drug Administration (FDA) approved an implanted retinal prosthesis to treat adult patients with advanced retinitis pigmentosa (RP), a rare genetic condition that damages the retina and leads to blindness. A small video camera mounted on a pair of glasses sends images to a video processing unit that converts them to electronic data that is wirelessly transmitted to an array of electrodes implanted onto the retina. The device is enabling those who are otherwise completely blind to identify doors, crosswalks, and even utensils on a table. Although this "Bionic Eye" may have been a fantasy just a few short years ago, the NEI has always envisioned the future. Funding must be adequate for it to successfully pursue its goal of saving and restoring vision.

BLINDNESS AND VISION LOSS IS A GROWING PUBLIC HEALTH PROBLEM THAT
INDIVIDUALS FEAR AND WOULD TRADE YEARS OF LIFE TO AVOID

The NEI estimates that more than 38 million Americans age 40 and older experience blindness, low vision, or an age-related eye disease such as AMD, glaucoma, diabetic retinopathy, or cataracts. This is expected to grow to more than 50 million Americans by year 2020. Although the NEI estimates that the current annual cost

of vision impairment and eye disease to the U.S. is \$68 billion, this number does not fully quantify the impact of indirect healthcare costs, lost productivity, reduced independence, diminished quality of life, increased depression, and accelerated mortality. NEI's proposed fiscal year 2014 funding of \$699 million reflects just a little more than 1 percent of this annual cost of eye disease. The continuum of vision loss presents a major public health problem, as well as a significant financial challenge to both the public and private sectors.

Vision loss also presents a real fear to most citizens:

- In public opinion polls over the past 40 years, Americans have consistently identified fear of vision loss as second only to fear of cancer. NEI's Survey of Public Knowledge, Attitudes, and Practices Related to Eye Health and Disease reported that 71 percent of respondents indicated that a loss of their eyesight would rate as a "10" on a 1 to 10 scale, meaning greatest impact on their life.
- In patients with diabetes, going blind or experiencing vision loss rank among the top four concerns about the disease. These patients are so concerned about vision loss diminishing their quality of life that those with nearly perfect vision (20/20 to 20/25) would be willing to trade 15 percent of their remaining life for "perfect vision," while those with moderate impairment (20/30 to 20/100) would be willing to trade 22 percent of their remaining life for perfect vision. Patients who are legally blind from diabetes (20/200 to 20/400) would be willing to trade 36 percent of their remaining life to regain perfect vision.

NAEVR URGES CONGRESS TO FUND NIH AT \$32 BILLION, NEI AT \$730 MILLION, IN FISCAL YEAR 2014 TO ENSURE THE MOMENTUM OF RESEARCH, TO RETAIN TRAINED PERSONNEL, AND MAINTAIN U.S. LEADERSHIP

ABOUT NAEVR

NAEVR, which serves as the "Friends of the NEI," is a 501(c)4 non-profit advocacy coalition comprised of 55 professional (ophthalmology and optometry), patient and consumer, and industry organizations involved in eye and vision research. Visit NAEVR's Web site at www.eyersearch.org.

PREPARED STATEMENT OF THE NATIONAL ALOPECIA AREATA FOUNDATION (NAAF)

NAAF Fiscal Year 2014 LHHS Appropriations Recommendations

- Protect medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.
- \$7.8 billion for CDC, an increase of \$1.7 billion over fiscal year 2012.
- \$32 billion for NIH, an increase of \$1.3 billion over fiscal year 2012.

Chairman Harkin, Ranking Member Moran, and distinguished members of the subcommittee, thank you for the opportunity to submit testimony on behalf of NAAF. It is my privilege to represent the great group of individuals affected by the autoimmune disease alopecia areata.

About the Foundation and Our Research

NAAF, headquartered in San Rafael, CA, supports research to find a cure or acceptable treatment for alopecia areata, supports those with the disease, and educates the public about alopecia areata. NAAF is governed by a volunteer Board of Directors and a prestigious Scientific Advisory Council. Founded in 1981, NAAF is widely regarded as the largest, most influential, and most representative foundation associated with alopecia areata. NAAF is connected to patients through local support groups and also holds an important, well-attended annual conference that reaches many children and families.

Recently, NAAF initiated the Alopecia Areata Treatment Development Program (TDP) dedicated to advancing research and identifying innovative treatment options. TDP builds on advances in immunological and genetic research and is making use of the Alopecia Areata Clinical Trials Registry which was established in 2000 with funding support from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); NAAF took over responsibility financial and administrative responsibility for the Registry in 2012 and continues to add patients to it. NAAF is engaging scientists in active review of both basic and applied science in a variety of ways, including the November 2012 Alopecia Areata Research Summit featuring presentations from the Food and Drug Administration (FDA) and NIAMS.

At the Research Summit Dr. Angela Christiano of Columbia University, discoverer of the genetic basis of alopecia areata, presented her progress in genetics research. A joint analysis performed with an independent genome-wide association study (GWAS) of 1435 cases and 2032 controls resulted in the validation of previous

GWAS targets and the identification of new associated genes. Some of these associated genes are unique to the hair follicle in alopecia areata. Dr. Christiano discussed targeting the IFN signature in the treatment of alopecia areata. She also discussed the genetic relationship between alopecia areata and other autoimmune diseases including the minimal overlap with psoriasis or vitiligo. This work greatly expands our understanding of the genetic architecture of this highly prevalent autoimmune disease.

Later this year the Proceedings of the Summit will be published in the *Journal for Investigative Dermatology (JID)*. The participants will be finalizing the goals for the next 2 years to be met by the following Alopecia Areata Research Summit in the fall of 2014. Those goals include:

Genetics:

- Execute combined association and linkage studies using 250 multiplex families from the Alopecia Areata Registry
- Utilize functional genomics with deep sequencing
- Develop network pilot
- Analyze shared variants with related diseases including celiac disease, rheumatoid arthritis, type 1 diabetes; 5 loci shared between type 1 diabetes and alopecia areata
- Develop a biobank
- Determine if there is a genetic basis for disease subsets, i.e. alopecia areata patchy, alopecia areata totalis, alopecia areata universalis
- Increase alopecia areata samples to 10,000

Immunology:

- Study how to restore immune privilege
- Analyze the potential of targeting IL-15 pathway
- Identify the protolerance TCR signal; then target it pharmacologically
- Develop T cell receptor sequencing
- Complete biomarker studies

Animal Models:

- Identify and develop mouse and humanized mouse models
- Validate models
- Determine which model will be the best to replicate alopecia areata

Clinical:

- Finalize and validate Alopecia Areata Uniform Protocol
- Publish quality of life studies
- Publish incidence and prevalence studies
- Initiate burden of diseases studies
- Use pharmacogenomics to predict patient populations that will respond and which will get side effects
- Determine the attractive pathways for targeted therapy
- Continue collaborations with industry and Government agencies to facilitate the regulatory path for alopecia areata treatments

About Alopecia Areata

Alopecia areata is a prevalent autoimmune skin disease resulting in the loss of hair on the scalp and elsewhere on the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis).

Alopecia areata affects approximately 2 percent of the population, including more than five million people in the United States alone. The disease disproportionately strikes children and onset often occurs at an early age. This common skin disease is highly unpredictable and cyclical. Hair can grow back in or fall out again at any time, and the disease course is different for each person. In recent years, scientific advancements have been made, but there remains no cure or indicated treatment options. We do not have known biomarkers at this time but an NIH-funded study is seeking to identify biomarkers.

The true impact of alopecia areata is more easily understood anecdotally than empirically. Affected individuals often experience significant psychological and social challenges in addition to the biological impact of the disease. Depression, anxiety, and suicidal ideation are health issues that can accompany alopecia areata. The knowledge that medical interventions are extremely limited and of minor effectiveness in this area further exacerbates the emotional stresses patients typically experience.

Deficit Reduction and Sequestration

As you work with your colleagues in Congress on deficit reduction, budget, and appropriations issues please support the alopecia areata community by actively pur-

suings meaningful funding increases for critical medical research and healthcare programs. Our Nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH currently supports a modest, but integral research portfolio in alopecia areata. The research funded through this portfolio is conducted at academic health centers across the country, which has a direct impact on local economic activity. Further, while more work needs to be done, the commitment to NIH's alopecia areata research portfolio over the years has greatly increased our scientific understanding of the condition.

If Federal funding for alopecia areata research is substantially reduced, the current effort to capitalize on recent advancements and develop treatment options will face a serious setback. Ongoing research projects will stall and critical new research projects will not be initiated. In addition, reducing support for Federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. The damage done now to the research training and career development pipeline could last for decades and undermine this country's entire biomedical research industry. It should also be noted that the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure.

The alopecia areata community is very concerned that if healthcare programs endure significant funding cuts, patients will see few improvements in health and healthcare over the coming years.

Centers for Disease Control and Prevention

NAAF joins with other voluntary health organizations in requesting that you support CDC by providing an allocation of \$7.8 billion in fiscal year 2014. This appropriation should include proportional funding increases for the various centers and programs at CDC, most notably the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

The alopecia areata community could benefit greatly from an analysis of prevalence, incidence, and associated demographic information by CDC. Further, awareness programs could reach children who have not been diagnosed with the condition and who are struggling to understand what is going on with their bodies. Finally, healthcare professionals could benefit from education and awareness activities that would promote proper diagnosis of alopecia areata and appropriate intervention. To initiate new programs that have the potential to improve health outcomes for alopecia areata patients or patients dealing with other condition, CDC would require a meaningful infusion of additional resources. Without additional resources, CDC will be unable to support current programs and activities and forced to forego many emerging opportunities.

National Institutes of Health

NAAF joins with the broader public health community in requesting that you support NIH by providing an allocation of \$32 billion in fiscal year 2014. This appropriation should include proportional funding increases for the various NIH Institutes and Centers, particularly NIAMS, the National Institute of Allergy and Infectious Diseases (NIAID), the National Center for Advancing Translational Research (NCATS), and the Office of the Director.

NIAMS supports the bulk of alopecia areata research currently conducted through NIH. In order to capitalize on this research and further improve our scientific understanding of the condition, NIH requires additional resources to expand and advance the alopecia areata research portfolio. NIH is presently foregoing meritorious research opportunities and additional funding would allow more of these grants applications to be funded.

NIAID.—Innovative new research activities initiated through NIAID into alopecia areata would add-value to NIAID's current research projects by leading to breakthroughs that could impact additional autoimmune conditions.

NCATS.—Clinical and translational research are of tremendous importance to the alopecia areata community. Expanding the Federal commitment to NCATS would allow the Center to work more effectively with FDA to facilitate the development of treatment options for conditions that currently lack treatments with an FDA indication.

OD.—Due to the autoimmune and genetic components of alopecia areata, research in this area has a significant cross-cutting value. Innovative research activities initiated and coordinated by OD could improve our understanding of both autoimmune conditions and conditions with genetic components.

Thank you for your time and your consideration of these requests. Please contact me if you have any questions or if you would like any additional information.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Introduction

Chairman Harkin, Ranking Member Moran, and Distinguished members of the subcommittee: My name is Dan Hawkins, and I am the Senior Vice President for Public Policy and Research at the National Association of Community Health Centers. On behalf of the American health center community, including the more than 22 million patients served nationwide by health centers, the 153,000 full-time health center staff, and countless volunteer board members who serve our centers as well as the National Association of Community Health Centers, we thank you for this subcommittee's strong bipartisan support of health centers. I also wish to thank you for the opportunity to submit testimony for the committee to review as you craft the fiscal year 2014 Labor-Health and Human Services-Education and Related Agencies Appropriations bill.

Health Centers—General Background

Health Centers are community-owned non-profit entities providing primary medical, dental, and behavioral health care as well as pharmacy and a variety of enabling and support services. Today, there are over 1,200 health centers operating at more than 9,000 urban and rural locations nationwide serving as medical homes for more than 22 million patients in all 50 States, including all of the States represented by the members of this subcommittee.

By statute and mission, health centers are located in medically underserved areas or serve a medically underserved population. This has enabled health centers to become health care homes to the medically underserved and our Nation's most vulnerable populations.

Health centers are also directed by patient -a majority board, which helps to ensure they are responsive to each individual community they serve, providing comprehensive primary care to all residents of the community who seek their care, regardless of ability to pay or insurance status and offer services on a sliding fee scale. This unique model ensures that health center operations are locally-controlled and responsive to each individual community's needs and, at the same time, reduce barriers to accessing health care.

Approximately 39 percent of Health Center patients are covered by Medicaid and another 36 percent are uninsured. In return, health centers bring significant value to the Medicaid program, serving 15 percent of Medicaid patients for only 1 percent of total Medicaid spending. Our unique model of care has enabled us to save the entire health system, including the Government and taxpayers, approximately \$24 billion annually. Health Centers also reduce preventable hospitalizations and Emergency Department (ED) use, as well as the need for more expensive specialty care. The services provided at health centers save \$1,200 per patient per year compared to expenditures for non-health center users. A *Journal of Rural Health* article entitled: Presence of Community Health Center and Uninsured Emergency Department Visit Rates in Rural Counties, written by Dr. George Rust et al, found that counties with a community health center site had 25 percent fewer uninsured ED visits. Without access to primary care, many people delay seeking health care until they are seriously ill and require inpatient hospitalization or care at an emergency room at a much higher cost. Health centers can help reduce those unnecessary costs by serving as health care homes for the underserved.¹

In addition to reducing health care costs, health centers can also serve as small businesses and economic drivers in their communities. In 2012, health centers employed 153,000 individuals and in 2009 generated \$20 billion in total economic benefits in poor urban and rural communities.

Fiscal Year 2013 Funding Background

In fiscal year 2013, health centers are slated to receive a total of \$3.1 billion in total Federal funding. This includes \$1.58 billion in discretionary funding provided by the Health Resources and Services Administration (HRSA) and \$1.5 billion in mandatory funding for health centers through the Affordable Care Act. This was a total increase of \$300 million from fiscal year 2012. A portion of this increase in

¹ Rust George, et al. "Presence of a Community Health Center and Uninsured Emergency Department Visit Rates in Rural Counties." *Journal of Rural Health* Winter 2009 25(1):8–16.

funding will go toward applications currently at HRSA. In January, HRSA released the fiscal year 2013 Affordable Care Act New Access Point (NAP) funding opportunity announcement. The NAP guidance solicited applications to award \$19 million to support 25 NAP awards. The application process closed in April with approximately 400 applications for the anticipated 25 awards, again demonstrating a significant need and demand for access in many communities. We expect that the number of applications would have been even higher if HRSA had announced a larger anticipated amount of awards.

As you know, the President's fiscal year 2013 Health Resources and Services Administration (HRSA) fiscal year 2013 budget proposal also requested total funding of \$3.1 billion. However, the Administration proposed holding back \$280 million of the total increase of \$300 million. The Senate, recognizing the pressing need for primary care, included language in the Consolidated and Further Continuing Appropriations Act of 2013 ensuring the full \$300 million be spent by the end of fiscal year 2013. We want to thank the subcommittee for their efforts and support for increased funding in fiscal year 2013 which will allow us to continue to work towards our shared goal of expanding access to quality and affordable health care to all Americans. We are grateful to our Senate supporters who worked to include this critical provision.

To date, only the discretionary funding health center fiscal year 2013 spend plan has been released by HRSA. This plan reflects the discretionary sequester reduction to the Health Center Program of \$79 million and an additional transfer of \$15 million from the program. We await the second half of HRSA's fiscal year 2013 spend plan and hope it will recognize the current and looming demand for increased access to primary care.

Increasing and Overwhelming Demand for Access to Primary Care

Today, 60 million Americans lack regular access to primary care, even as the Nation is preparing to provide health coverage for as many as 30 million newly-insured Americans. Health centers stand ready to do their part to meet these enormous challenges of providing a health care home for these individuals. Even with the investment made in the Health Center Program, barriers to care make it difficult for individuals to access primary care and the demand for primary care far exceeds the supply across the Nation, but health centers can play a role in solving this crisis.

NACHC recently released a report entitled: Health Wanted, the State of Unmet Need for Primary Health Care in America ("Health Wanted") which States that barriers to accessible care including affordability, accessibility, and availability can diminish access to primary care. Health Wanted demonstrated that when health centers are located in medically underserved areas, using the unique health center model they are able to overcome these barriers to care and are able to improve health care outcomes as well as reduce health care costs. But the demand for health centers continues to outpace growth. Health Wanted also highlights the fact that at least 25 percent of U.S. counties in greatest need do not have a health center.²

Health centers can meet these primary care demands with proper resources. This means fully leveraging the funds available to health centers to expand the number of health centers throughout the country. We look forward to working with this subcommittee to ensure the promise of access to primary care becomes a reality in all underserved communities that currently lack it.

Fiscal Year 2014 Funding Request

The President's proposed fiscal year 2014 Health Resources and Services Administration (HRSA) budget provides \$1.58 billion in discretionary funding for the Health Centers program. Together with the \$2.2 billion in fiscal year 2014 mandatory funding available for health centers, health centers could receive a net increase of \$700 million in total programmatic funding for fiscal year 2014 equaling total funding of \$3.8 billion.

We strongly support the President's proposed funding level of \$3.8 billion for health centers as it provides the opportunity for continued growth of the Health Center program in the face of overwhelming need. The \$700 million increase could enable health centers to expand access to care to more than 5 million new patients. Health Centers are looking ahead as the demand for primary care is expected to soar as millions receive health coverage for the first time, many of them living in the very communities we serve. Health centers will become the health care home for many of these new patients. We must create the capacity to serve these patients. If primary care is not accessible in the communities in which these people live, they

² NACHC and the Robert Graham Center. Help Wanted: The State of Unmet Need for Primary Care in America. March 2012. www.nachc.com/client/HealthWanted.pdf.

will seek it out in emergency departments and hospitals, often when they are sicker. This will mean poorer health for these patients and much higher costs to the system.

Health Centers are respectfully requesting a total of no less than \$3.8 billion in funding for the Health Center program and that the full \$700 million increase be spent in fiscal year 2014 to increase access to primary care. We propose that the entire increase be used immediately to provide for the expansion of care to 5 million new patients and we look forward to working with you to ensure that this subcommittee's funding priorities as well as the needs of health centers across the country are communicated and realized as a part of the fiscal year 2014 funding process.

Conclusion

We understand this subcommittee will have to make many difficult budgetary decisions as you work within the funding limits set for the fiscal year 2014 Labor-Health and Human Services-Education Appropriations bill.

As the fiscal year 2014 appropriations process moves forward, we urge you to keep in mind that without their local health center, medically underserved communities and patients would often be without any access to primary care. Health Centers are more than a safety net, they have a demonstrated track record of improving the health and well-being of their patients using a locally-tailored health care home model designed to coordinate care and manage chronic disease at the same time reducing unnecessary, avoidable and wasteful use of health resources.

Health centers have continually proven to be a worthwhile investment by delivering high quality, affordable health care while generating savings to the entire health system. We are extremely grateful for your leadership and ask for the subcommittee's continued support for the Health Center program.

We look forward to working with you and thank you for your consideration.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION FOR STATE COMMUNITY SERVICES PROGRAMS

Chairman Tom Harkin, Ranking Member Thad Cochran, members of the committee, thank you for the opportunity to submit this testimony on behalf of the National Association for State Community Services Programs (NASCS), the premier national association representing State administrators of the Department of Health and Human Services' Community Services Block Grant (CSBG) and State directors of the Department of Energy's Low-Income Weatherization Assistance Program. We thank Congress for its past support of CSBG and look forward to working with you to build on the past success and to promote economic mobility for all Americans in the years ahead. We appreciate your support and need it now more than ever as more Americans face economic insecurity. NASCS seeks continued funding of \$713.63 million for CSBG in fiscal year 2014 in order to build on the successes of the CSBG Network. With level funding, we believe that this already proven network, built on local solutions to community issues, is the Nation's answer to the economic plight that many Americans experience.

Why CSBG, Why Now

At a time when over 46 million Americans are living below the Federal poverty level (\$23,550 a year for a family of four), Americans support effective public solutions to this pressing issue. Americans need solutions like CSBG to bridge the gap between falling wages, job shortages, and high costs of living to keep them from slipping further into poverty. The strength of our Nation depends on the prosperity of its citizens. CSBG can facilitate that prosperity and opportunity for all Americans. The CSBG Network is a proven provider of anti-poverty programs, supporting millions of low-income Americans on the path to economic security and self-sufficiency. By taking a local approach, the CSBG Network uses grassroots, innovative strategies to alleviate poverty and provides a significant return on taxpayers' investment. In 2011, the CSBG Network leveraged \$23.43 for every dollar of CSBG funding.

Background of CSBG

CSBG is a federally-funded block grant that supports local anti-poverty efforts through State-administered networks of more than 1,000 CAAs that work to eliminate poverty, revitalize low-income communities, and empower low-income families to become self-sufficient and economically secure. State administrators of CSBG are committed to ending poverty and maintaining high accountability standards through monitoring and technical assistance. As a conduit between the Federal administration and agencies, States build public-private partnerships, support innova-

tion, and advance best practices to ensure the most effective use of taxpayers' money. Local agencies utilize CSBG funds to leverage additional resources and to eliminate poverty through a variety of programs and services. While CAAs across the Nation address similar issues, local needs determine unique approaches to addressing them. Poverty, while a national problem, looks different in every community. The CSBG Network strives to find local solutions to these community issues by conducting community needs assessments to identify with the needs, challenges, and resources in a local community. The community needs assessments enables CAAs to provide the most effective and efficient programs and services, which fall into nine service categories outlined in the CSBG Act; employment, education, income management, housing, emergency services, nutrition, linkages, self-sufficiency, and health.

National data compiled by NASCSP shows that CSBG serves a broad segment of low-income individuals and families. Data from fiscal year 2011 shows:

- There are 1,048 CAAs across the country, serving 99 percent of U.S. counties.
- CSBG serves one out of every five people in America below the Federal Poverty Guideline.
- The majority of clients are female (58 percent), white (59.1 percent), renters (60 percent), and between the ages of 24 to 54 years old (36 percent)—the second largest group was seniors over the age of 55 (18 percent).
- Many of the families served were in “severe poverty” (32.3 percent), with incomes below 50 percent of the Federal Poverty Guideline.

Successes of the CSBG Network

Highlights of the CSBG Network

- CSBG served 18.7 million Americans, including 7.6 million families in fiscal year 2011,
- Over the past 5 years, the CSBG Network has:
 - Helped over 645,000 people obtain a job,
 - Addressed 18 million barriers to employment through helping people acquire a job, obtain employment supports, and/or receive job training,
 - Expanded 21.5 million community opportunities or resources, which helped to stimulate community and economic development, and
 - Facilitated 17.7 million opportunities for infants, children, youth, parents, and other adults through developmental or enrichment programs.

Success Stories of the CSBG Network

Job Skills Training in Georgia Leads to Employment—Coastal Plain Area Economic Opportunity Authority, Inc.

The Coastal Plain Area Economic Opportunity Authority, Inc. (Coastal Plain) contributed to improving the employment outlook in their community by creating programs that addressed the needs identified through a community needs assessment the agency conducted in 2010. Coastal Plain found that the number of unemployed individuals in their community increased significantly, and that many of those unemployed individuals lacked the communication and the job-hunting skills necessary to obtain work in a competitive job market. Coastal Plain created a job-seeker training program that prepared participants for a successful job search by teaching them how to write a comprehensive resume and provided interview tactics to best convey their experience and knowledge to potential employers.

Coastal Plain also created linkages with local businesses, which donated interview clothing and supplies, and community organizations, which offered job leads, career fairs, continuing education opportunities, and online job search tools. The agency met childcare needs by partnering with the State Department of Family and Children Services to secure affordable childcare. In 2011, of the 470 people who completed the program, 125 have found employment and the others continue to receive assistance with their job searches. As a CAA, Coastal Plains had the capacity to look at the needs of the community, develop a program to meet those needs, and provide comprehensive services to support job-seekers.

Helping Seniors Maintain Independent Living in Arizona—Community Action Human Resources Agency

Living at home allows low-income seniors and disabled individuals to maintain their independence, which improves their quality of life—and saves taxpayers money. The Community Action Human Resources Agency (CAHRA) created the Home Alone Safe Alone (HASA) program to provide Pinal County seniors and disabled individuals with emergency notification devices that allowed them to remain independent without sacrificing their security and safety. This program is cost-effective and successful because it combines CSBG funds together with volunteer hours.

CAHRA provides an Emergency Alert Pendant at no cost to income-eligible participants thanks to a partnership with the United Way, who covers the costs of the equipment. CSBG-funded CAHRA staff coordinates the program, the partners, and trained volunteers who install all safety hardware. Since the program began 9 years ago, CAHRA has helped nearly 1,000 low-income seniors and disabled individuals remain safe, secure, and independent through the HASA program, including providing 227 devices to needy seniors and disabled individuals in the 2010 program year.

Innovative Gardening in New York—Community Action of Orleans and Genesee, Inc.

Recognizing that effective use of work release time for individuals incarcerated by the criminal justice system provides benefits to both the inmate and the local community, Community Action of Orleans and Genesee, Inc. reached out to a local prison facility to make efficient use of their land and inmate work release time through the Facility Garden Project.

Through this collaboration, inmates plant, weed, and harvest fruits and vegetables with facility staff. They distribute these fruits and vegetables to the CAA and other nutrition programs. These local organizations in turn provide 800 low-income families with both raw food and prepared meals. The Facility Garden Project positively impacts low-income families and partner agencies in all of Orleans County and parts of Genesee County. In fiscal year 2010, agencies across the service area helped distribute more than 3,000 pounds of assorted vegetables to disabled seniors, soup kitchen customers, emergency food customers, and low-income families.

This innovative partnership yields positive results for the prison, community agencies, and low-income residents. CSBG funds were essential in creating this collaboration by funding project planners, staff who distributed the food to consumers, storage space for the vegetables, and space for cooking classes.

Closing Statement

CAAs funded by the CSBG are an important link in the social safety net. They comprise a nationwide, accountable network that has experience in developing innovative, high-impact anti-poverty strategies and programs that are based on local needs. The CSBG Network uses resources to leverage more than \$23 for each dollar of CSBG funds invested. CSBG bridges the gap between falling wages, job shortages, and high costs of living to keep working Americans from slipping further into poverty. CSBG already serves one out of every five people in America below the Federal Poverty Guideline. Strengthening CSBG is an effective, efficient way to meet our Nation's need for a strong and successful effort to bring economic opportunity to every American.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF COUNTY AND CITY HEALTH OFFICIALS

FISCAL YEAR 2014 FUNDING FOR PROGRAMS AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

[\$ in millions]

Program	Fiscal Year 2012	Fiscal Year 2013	Fiscal Year 2014 Pres. Budget	NACCHO Fiscal Year 2014 Request
Prevention and Public Health Fund	1,000	949	1,000	1,000
CDC Public Health Emergency Preparedness Grants	666	608	658	715
CDC Community Transformation Grants	226	146	146	280
CDC Section 317 Immunization Program	642	528	581	642
CDC National Public Health Improvement Initiative	40	37	40	40
CDC Food Safety	27	26	49	49

The National Association of County and City Health Officials is the voice of the 2,800 local health departments across the country. These city, county, metropolitan, district, and tribal departments work every day to ensure the safety of the water we drink, the food we eat, and the air we breathe.

More than 180,000 health department staff across the country are responsible for programs that make it easier for people to be healthy. The Nation's current financial challenges are compounded by those in State and local governments further di-

minishing the ability of local health departments to address community health and safety needs. Repeated rounds of budget cuts and lay-offs continue to erode local health department capacity. Since 2008, local and State health departments have scaled back and eliminated programs that protect the public's health and cut more than 50,000 jobs. Sequester cuts will add to pressures on local health departments as Federal cuts make their way down to the State and local level.

To help protect the public's health, we urge the subcommittee to consider the following fiscal year 2014 funding request for programs at the Department of Health and Human Services (HHS) and Centers for Disease Control and Prevention (CDC):

Prevention and Public Health Fund (HHS)

NACCHO Request: \$1 billion

Fiscal Year 2014 President's Budget: \$1 billion

Fiscal Year 2013: \$949 million

The Prevention and Public Health Fund (PPHF) is a dedicated Federal investment in programs that prevent disease at the community level. The PPHF supports:

- Early and rapid detection of diseases and injury;
- Continuous quality improvement in public health practice;
- Community-based initiatives to stem the epidemic of preventable disease;
- Immunizations and innovative chronic disease grants to prevent and reduce the rising cost of health care for the leading causes of death; and
- Local and State public health workforce training.

In fiscal year 2013 the Obama Administration diverted more than \$300 million from the PPHF for Navigator grants and health reform implementation. NACCHO urges Congress to act to outline an allocation for the \$1 billion available from the PPHF in fiscal year 2014 that adheres to its statutory purpose to prevent disease and promote public health.

Public Health Emergency Preparedness

Center: Center for Public Health Preparedness and Response

Funding Line: State and Local Preparedness and Response Capability

Sub-line: Public Health Emergency Preparedness Cooperative Agreements (PHEP)

NACCHO request: \$715 million

Fiscal Year 2014 President's Budget: \$658 million (fiscal year 2014 President's Budget includes PHEP grants in State and Local Preparedness and Response Capability)

Fiscal Year 2013: \$608 million

The Public Health Emergency Preparedness (PHEP) grant program protects communities by strengthening local and State public health department capacity to effectively respond to public health emergencies including terrorist threats, infectious disease outbreaks, natural disasters, and biological, chemical, nuclear, and radiological emergencies. Local and State health departments work with Federal officials, law enforcement, emergency management, health care, employers, schools, and religious groups to plan, train, and prepare for emergencies so that communities are ready. Local health departments protect the public in the following ways:

- They investigate, detect, and contain outbreaks of disease
- They educate the public about how to protect themselves; such as by wearing masks, drinking bottled water, or staying indoors.
- They dispense medications or vaccinations to slow the spread of illness.

The PHEP program has lost more than a quarter of its funding since fiscal year 2004. Sustained funding is essential to make sure that communities are protected.

Chronic Disease Prevention

Center: Center for Chronic Disease Prevention and Health Promotion

Funding Line: Community Transformation Grants (CTG)

NACCHO Request: \$280 million

Fiscal Year 2014 President's Budget: \$146 million

Fiscal Year 2013: \$146 million

The CTG program provides resources for local communities to address heart attacks, strokes, cancer, diabetes, and other chronic diseases which contribute to the soaring cost of health care. Risk factors like obesity and smoking often lead to these diseases and conditions, which are responsible for 75 percent of all health care spending—96 cents per dollar for Medicare and 83 cents per dollar for Medicaid. CTG grantees are charged with a 5 percent reduction in 5 years of death and disability due to tobacco use, heart disease and stroke and the rate of obesity through nutrition and physical activity. The program seeks to improve the health of about 130 million Americans.

Infectious Disease Prevention

317 Immunization Program

Center: National Center for Immunization and Respiratory Diseases

Funding Line: 317 Immunization Program

NACCHO Request: \$642 million

Fiscal Year 2014 President's Budget: \$581 million

Fiscal Year 2013: \$528 million

Local health departments vaccinate people in their communities, providing one of the most successful and cost-effective ways to prevent disease and death. Local health departments use innovative methods to increase vaccination rates, including "Vote and Vax" activities where voters receive immunizations at their polling places and conducting outreach to families to make sure kids are immunized and ready to attend school.

Local health departments also have a responsibility for ensuring that the most vulnerable people in their communities receive protection from vaccines. The Section 317 Immunization Program provides funds to 50 States, six large cities and eight territories for vaccine purchase for at-need populations and immunization program operations at the local, State, and national levels. Local health departments utilize these funds to work with public and private physicians to assure effective immunization practices, including proper storage and delivery of vaccines. Through the use of vaccine registries administered by health departments, savings are achieved by avoiding duplicative vaccinations, improved inventory management, and by identifying gaps in immunizations in persons and groups.

Sustained funding for the Section 317 is critical to protecting Americans for preventable diseases. NACCHO supports the President's request of \$25 million within 317 funding to support State and local health departments to develop billing and other infrastructure that is needed to be reimbursed for clinical services.

Public Health Performance Improvement

Center: Center for Public Health Leadership and Support

Funding Line: National Public Health Improvement Initiative

NACCHO Request: \$40 million

Fiscal Year 2014 President's Budget: \$40 million

Fiscal Year 2013: \$37 million

The National Public Health Improvement Initiative provides funding to 74 State, tribal, local and territorial health departments to make changes and enhancements that increase the impact of public health services. NPHII strengthens health departments by providing staff, training, tools, and capacity-building assistance dedicated to establishing performance management and evidence-based practices for improved service delivery and better health outcomes.

Food Safety

Center: Center for Emerging and Zoonotic Infectious Diseases

Funding Line: Food Safety

NACCHO Request: \$49 million

Fiscal Year 2014 President's Budget: \$49 million

Fiscal Year 2013: \$26 million

Foodborne illness affects 48 million Americans every year, resulting in 128,000 hospitalizations and 3,000 deaths. CDC's Food Safety program seeks to ensure food safety through surveillance and outbreak response. Local and State health departments are an essential part of the process that ensures that food is safe to eat at home, at community events, in restaurants, and in schools. Funding is needed to advance implementation of the Food Safety Modernization Act by enhancing and integrating disease surveillance, improving outbreak and response timeliness and helping address deficits in local capacity to prevent and stop illness.

As the subcommittee drafts the fiscal year 2014 Labor-HHS-Education Appropriations bill, NACCHO urges consideration of these recommendations for programs critical to protecting the public's health.

 PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS
Introduction

The National Congress of American Indians (NCAI) is the largest and oldest representative organization of American Indian and Alaska Native tribal governments. NCAI represents the broad interests of tribes and their citizens to advance, and promote the advancement, of tribal Sovereignty and Self-Determination. NCAI respect-

fully submits this testimony on the Corporation for Public Broadcasting (CPB) and programs in the Department of Labor.

CORPORATION FOR PUBLIC BROADCASTING

In the CPB, NCAI supports an advanced fiscal year 2015 appropriation of \$5 million for American Indian and Alaska Native radio stations. This \$5 million appropriation would come out of the fiscal year 2014 advanced appropriation of \$445 million for the overall CPB budget.

For more than 30 years, decisions on the amount of Federal support for public broadcasting have been made 2 years ahead of the fiscal year in which the funding is allocated. In other words, Congress approves the fiscal year 2015 funding level for CPB during the fiscal year 2013 appropriations process. Thus, where the overall budget for the CPB in fiscal year 2014 was \$445 million, Indian Country requests an advance appropriation of \$5 million to fund American Indian and Alaska Native radio stations for fiscal year 2015.

Since 2011, the Native radio system has grown from 33 stations to 53 stations to provide service to more of Indian Country. CPB funding supports 30 of 53 Native radio stations, which collectively reach more than 8 percent of the American Indian and Alaska Native populations with free radio programming. These stations are funded through a variety of sources, including: individual donors, local businesses, CPB, tribal governments, and grants. Native-owned and operated radio stations are a model of local community service radio, serve as the primary and most consistent sole service providers of public safety information and cultural and linguistic preservation, and stand as an invaluable outlet for local news in tribal communities. Native radio stations employ at least 1,000 broadcasters, engineers, station staff, consultants, and other local community members.

Additionally, the Public Broadcasting Act directs CPB to utilize 6 percent of the appropriation for “projects and activities that will enhance public broadcasting.” This funding supports the research, planning, professional development, and industry consultations that guide CPB’s decisionmaking in other budget categories. Native Public Media and Koahnic Broadcast Corporation are capable to provide valued services to develop and maintain the Native radio system and are funded from the 6 percent allocation (currently amounting to \$1 million over 2 years). Native Public Media has assisted in filing for 51 new stations and secured construction permits for 38 of these new stations.

Native Public Media also provides education and training for tribal broadcasters in digital literacy, journalism, and community-based strategies that will broaden the impact of the Native radio system in unserved tribal communities across the United States. Koahnic Broadcast Corporation produces Native programming and content for radio broadcast and oversees Native Voice One—the distribution mechanism that utilizes satellite technology to deliver programming and content to Native radio stations and other affiliates across the United States.

Native public radio stations still exist as one of the primary sources of public information on tribal lands, and represent cornerstones of tribal efforts for information dissemination. Much of Indian Country remains disconnected from vital telecommunications services, radio should not be counted among them. Radio has always existed as a key component of public information and 53 tribal radio stations among this country’s 566 federally recognized tribes illustrates the need for these services in Indian Country. This communications tool, though antiquated it may seem compared to other technologies available today, provides services of immense cultural significance.

DEPARTMENT OF LABOR

Restore the YouthBuild Program funding to a minimum of \$102.5 million, restore the rural and tribal set-aside in the YouthBuild program, and reinstate a dedicated 10 percent rural and tribal set-aside of at least \$10.25 million. The YouthBuild program is a workforce development program that provides significant academic and occupational skills training and leadership development to youth ages 16–24. YouthBuild provides services to approximately 7,000 youth annually by re-engaging them in innovative alternative education programs that provide individualized instruction as they work towards earning either a GED or high school diploma, as well as fosters work skills so that youth can be competitive candidates in the job market. Youth participate in public construction projects while attending classes to obtain their high school diploma or GED.

YouthBuild reports that since it was established as a Federal program in 1992, 120,000 YouthBuild students have built 22,000 units of affordable housing in low-income communities in 46 States and the District of Columbia. When the program

was transferred from the Department of Housing and Urban Development to the Department of Labor in 2007, the 10 percent set-aside for rural and tribal programs was eliminated. Additionally, in 2011, due to a 28 percent cut in YouthBuild appropriations, over 18,000 applicants to YouthBuild programs were turned away.¹

The YouthBuild program recruits youth that have been adjudicated, aged out of foster care, dropped out of high school, and others at risk of not having access to workforce training. In 2010, 4,252 youth participated in the program and had a completion rate of 78 percent. According to YouthBuild, 60 percent of those that completed the program were placed in jobs or further education.² There are a number of tribal YouthBuild programs in several States, and at least 4 percent of YouthBuild participants are Native. Given the recent reduction in tribal YouthBuild programs, significant unemployment and housing challenges in Indian Country, and the growing Native youth population, it is essential that the 10 percent rural and tribal set-aside be restored. 42 percent of the total American Indian and Alaska Native population is under 25³, and these workforce development opportunities are essential in preparing tribal youth for employment and self-sufficiency.

Fund the Department of Labor's Indian and Native American Program (INAP) at a minimum of \$60.5 million. Fund the Native American Employment and Training Council at \$125,000 from non-INAP resources. Reducing the education and employment disparity between Native people and other groups requires a concentrated effort that provides specific assistance to enhance education and employment opportunities, to create pathways to careers and skilled employment, and to secure a place for Native people within the Nation's middle class. The Workforce Investment Act (WIA) Section 166 program serves the training and employment needs of over 38,000 American Indians and Alaska Natives via a network of 175 grantees through the Comprehensive Service Program (Adult) and Supplemental Youth Service Program (Youth), and the Indian Employment and Training and Related Services Demonstration Act of 1992, Public Law 102-477. Furthermore, the number of American Indians and Alaska Natives served through WIA does not fully capture the impact it has in Indian Country, as there are many more served by grantees that leverage WIA funding, along with other similar federally funded employment and training programs, through PL 102-477.

Any decrease in funding along with the looming discretionary cuts will be devastating and severely hamper labor progress in Indian Country. According to the Census, the average unemployment rate on reservations dropped more than 3 percentage points since 2000⁴, but more still needs to be done as American Indians and Alaska Natives still lag significantly behind. With the average unemployment rate in Indian Country cited up to 17 percent⁵ and an average joblessness rate of nearly 50 percent⁶, the WIA Section 166 program is vital to helping reverse these trends.

Because the WIA Section 166 program is the only Federal employment and job training program that serves American Indians and Alaska Natives who reside both on and off reservations, it is imperative that its funding be maintained. For Native citizens living on remote reservations or in Alaska Native villages, it can be difficult to access the State and local workforce systems. In these areas, the WIA Section 166 program is the sole employment and training provider.

The Workforce Investment Act (the Act) has been up for reauthorization since 2003, and over this ten-year period, the Act has not accounted for the population growth of tribal communities, nor the economic environment that has drastically changed; according to the 2010 Census, the population of tribal communities has grown 27 percent since the year 2000, compared to 9 percent for the general population.⁷ The Act authorizes the INAP to be funded at "not less than \$55 million," but Section 166 is currently funded at approximately \$47 million. The Act also authorizes the Native American Employment and Training Council to advise the Secretary on the operation and administration of INAP, but is funded through the already strained and underfunded budget intended for INAP grantees. Since the current INAP funding is already below \$55 million, the Secretary should use other streams of funding to support its advisory council. Without an increase in funding and given the large increase in the American Indian and Alaska Native population,

¹ See <https://youthbuild.org/research>.

² *Ibid.*

³ U.S. Census Bureau, 2010 Census, Summary File 1.

⁴ US Census Bureau. Census 2000 Summary File 4, 2006-2010, 2009-2011 American Community Survey.

⁵ U.S. Census. 2011 American Community Survey.

⁶ U.S. Department of Interior. Bureau of Indian Affairs. 2005 American Indian Labor Force Report.

⁷ U.S. Census Bureau, 2010 Census, Summary File 1.

not enough tribes are able to benefit from the support and training activities for employment opportunities in Indian Country.

DEPARTMENT OF EDUCATION PROGRAMS

Introduction

The National Congress of American Indians (NCAI) is the oldest and largest American Indian organization in the United States. Tribal leaders created NCAI in 1944 as a response to termination and assimilation policies that threatened the existence of American Indian and Alaska Native tribes. Since then, NCAI has fought to preserve the treaty rights and sovereign status of tribal governments, while also ensuring that Native people may fully participate in the political system. As the most representative organization of American Indian tribes, NCAI serves the broad interests of tribal governments across the Nation.

Investing in the education of American Indian and Alaska Native students is not only one most of the most important cornerstones of the Federal trust responsibility to tribes, but is also critical to economic revitalization for both Indian Country and the Nation as a whole. President Obama has repeatedly stressed that improving American education is an “economic imperative,” and for tribes, the stakes are just as high, if not higher. Education provides tribal economies with a more highly-skilled workforce while also directly spurring economic development and job creation. The profound value of education for Native nations extends beyond just economics, however. Education drives personal advancement and wellness, which in turn improves social welfare and empowers communities—elements that are essential to maintaining tribes’ cultural vitality and to protecting and advancing tribal sovereignty.

Despite the enormous potential of education for transforming tribal communities, Native education is in a state of emergency. American Indian and Alaska Native students lag far behind their peers on every educational indicator, from academic achievement to high school and college graduation rates. For example, in 2011, only 18 percent of Native fourth graders and 22 percent of Native eighth graders scored proficient or advanced in reading, and only 22 percent of Native fourth graders and 17 percent of Native eighth graders scored proficient or advanced in math.⁸ The crisis of Indian education is perhaps most apparent in the Native high school dropout rate, which is not only one of the highest in the country, but is also above 50 percent in many of the States with high Native populations.⁹

To address this urgent situation and provide tribal nations with the critical foundation for economic success, the Federal Government must live up to its trust responsibility by providing adequate support for Native education. The requests below detail the minimum appropriations needed to maintain a system that is struggling and underfunded. NCAI also fully supports the recommendations of the American Indian Higher Education Consortium for tribal colleges.

Education Funding Requests For The Fiscal Year 2014 Labor-HHS-Education Bill

State-Tribal Education Partnership (STEP) Program

—Provide \$5 million for the State-Tribal Education Partnership Program.

Congress appropriated roughly \$2 million dollars for the STEP program to five participating tribes in fiscal year 2012 and fiscal year 2013 under the Tribal Education Department appropriations’ line that is administered by the Department of Education. In order for this program to continue to succeed and thrive, it must receive its own line of appropriations in fiscal year 2014. Collaboration between tribal education agencies and State educational agencies is crucial to developing the tribal capacity to assume the roles, responsibilities, and accountability of Native education departments and increasing self-governance over Native education.

Impact Aid

—Provide \$1.395 billion for Impact Aid, Title VIII of the Elementary and Secondary Education Act (ESEA).

Impact Aid provides direct payments to public school districts as reimbursement for the loss of traditional property taxes due to a Federal presence or activity, including the existence of an Indian reservation. With nearly 93 percent of Native students enrolling in public schools, Impact Aid provides essential funding for schools serving Native students. Therefore, funding for Impact Aid must not be less than

⁸National Indian Education Study 2011, NCES 2012–466. National Center for Education Statistics, Institute of Education Sciences, United States Department of Education.

⁹School Year 2010–2011 Four-Year Regulatory Adjusted Cohort Graduation Rates, Department of Education.

this requested amount. Furthermore, Impact Aid should be converted to a forward-funded program to eliminate the need for cost transfers and other funding issues at a later date.

Title VII (Indian Education Formula Grants)

—Provide \$198 million for Title VII of the ESEA.

This grant funding is designed to supplement the regular school program and assist Native students so they have the opportunity to achieve the same educational standards and attain equity with their non-Native peers. Title VII provides funds to school divisions to support American Indian, Alaska Native, and Native Hawaiian students in meeting State standards. Furthermore, Title VII funds support early-childhood and family programs, academic enrichment programs, curriculum development, professional development, and culturally-related activities.

Alaska Native Education Equity Assistance Program

—Provide \$35 million for Title VII, Part C of the ESEA.

This assistance program funds the development of curricula and education programs that address the unique educational needs of Alaska Native students, as well as the development and operation of student enrichment programs in science and mathematics. This funding is crucial to closing the gap between Alaska Native students and their non-Native peers. Other eligible activities include professional development for educators, activities carried out through Even Start programs and Head Start programs, family literacy services, and dropout prevention programs.

Native Hawaiian Education Program

—Provide \$35 million for Title VII, Part B of the ESEA.

This program funds the development of curricula and education programs that address the education needs of Native Hawaiian students to help bring equity to this Native population. Where Native Hawaiians once had a very high rate of literacy, today Native Hawaiian educational attainment lags behind the general population. The Native Hawaiian Education program empowers innovative culturally appropriate programs to enhance the quality of education for Native Hawaiians. When establishing the Native Hawaiian Education Program, Congress acknowledged the trust relationship between the Native Hawaiian people and the United States. Additionally, specific educational disparities were identified, and targeted for improvement. New grantees in fiscal year 2011 alone are estimated to provide educational programs to over 30,000 Native Hawaiian children and families. These programs strengthen the Native Hawaiian culture and improve educational attainment, both of which are correlated with positive economic outcomes.

Tribal Education Departments

—Provide \$5 million to fund Tribal Education Departments.

Five million dollars should be appropriated to the Department of Education to support tribal education departments (TEDs). This funding assists TEDs, which are uniquely situated at the local level to implement innovative education programs that improve Native education. Because they are administered by tribes, TEDs are best equipped to deliver education programs tailored to improve education parity for Native students. TEDs would use this much-needed funding to develop academic standards, assess student progress, and create math and science programs that require high academic standards for students in tribal, public, and Bureau of Indian Education schools. Tribes exercising self-governance over their citizens' education have been very successful because they better understand the circumstances of their populations and can develop initiatives that meet local needs. Adequately funding TEDs would create the most return on Federal dollars spent.

Vocational Rehabilitation Services Projects for American Indians with Disabilities

—Increase Vocational Rehabilitation Services Projects to \$67 million and create a line-item of \$5 million for providing outreach to tribal recipients.

According to the Centers for Disease Control and Prevention, approximately 30 percent of American Indian and Alaska Native adults have a disability—the highest rate of any other population in the Nation.¹⁰ Of those American Indian and Alaska Native adults with a disability, 51 percent reported having fair or poor health.¹¹ A number of issues contribute to this troubling reality, including high incidences of diabetes, heart disease, and preventable accidents. As a result, tribes have an extraor-

¹⁰Centers for Disease Control and Prevention. (2011). "Disability and Health". Retrieved on January 2, 2013, from <http://www.cdc.gov/ncbddd/disabilityandhealth/data.html>.

¹¹*Ibid.*

dinary need to support their disabled citizens in improving their health and becoming self-sufficient. Despite this need, however, tribes have had limited access to funding for vocational rehabilitation and job training compared to States. An increase in the Vocational Rehabilitation Services Projects to \$67 million would begin to put tribes on par with State governments and better equip tribes to provide supports to their disabled citizens.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Introduction

The National Congress of American Indians (NCAI) is the oldest and largest American Indian organization in the United States. Tribal governments cannot survive and prosper without healthy and strong tribal citizens. The United States Congress has shown a commitment to over 300 treaties and the Federal trust responsibility through appropriations to programs that support the health and wellness of tribal communities. However, American Indians and Alaska Natives continue to experience chronically high rates of foster care, suicide, diabetes, and obesity.

Each year NCAI works with national and regional Indian organizations to develop budget recommendations and requests for each area of the Federal budget. For this subcommittee, NCAI provides the recommendations below for some Federal agencies under the Department of Health and Human Services (HHS) and fully supports the recommendations of the National Indian Child Welfare Association, National Indian Health Board, and National Indian Education Association.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Provide \$15 million to fund Substance Abuse and Mental Health Services Administration (SAMHSA) for Behavioral Health.—This SAMHSA grant program has been authorized to award grants to Indian health programs to provide the following services: prevention or treatment of drug use or alcohol abuse, promotion of mental health, or treatment services for mental illness. To date, these funds have never been appropriated. An appropriation of \$15 million would provide support to Indian health programs to meet the critical substance abuse and mental health needs of their citizens.

Support SAMHSA's Behavioral Health Tribal Prevention Grant program at \$40 million in fiscal year 2014.—The Behavioral Health Tribal Prevention Grant will support behavioral health services that promote overall mental and emotion health, in particular substance abuse prevention and suicide prevention services. If funded, the grant program would be the only source of Federal substance abuse and suicide prevention funding exclusively available to tribes.

Provide a \$6 million tribal set-aside for American Indian suicide prevention programs under the Garrett Lee Smith Act.—Suicide has reached epidemic proportions in some tribal communities. The Garrett Lee Smith Memorial Act of 2004 is the first Federal legislation to provide specific funding for youth suicide prevention programs, authorizing \$82 million in grants over 3 years through SAMHSA. Currently, tribes must compete with other institutions to access these funds. To assist tribal communities in accessing these funds, a line item for tribal-specific resources is necessary.

Administration for Children and Families

Provide full funding for Head Start and Indian Head Start.—Head Start has been and continues to play an instrumental role in Native education. This vital program combines education, health, and family services to model traditional Native education, which accounts for its success rate. However, current funding dollars provide less for Native populations as inflation and fiscal constraints increase. It is now conventional wisdom that there is a return of at least \$7 for every single dollar invested in Head Start.¹² Therefore, Congress should fully fund Head Start and Indian Head Start to ensure this highly successful program serves more Native people.

Provide \$10 million for Esther Martinez Program Native language preservation grants.—Native language grant programs are essential to revitalizing Native languages and cultures, many of which are at risk of disappearing in the next decades. With adequate funding, Esther Martinez Program Grants support and strengthen Native American language immersion programs. In addition to protecting Native languages, these immersion programs have been shown to promote higher academic success for participating students in comparison to their Native peers who do not

¹² Mitra, D. (June 2011). "Pennsylvania's best investment: The social and economic benefits of public education." Philadelphia, PA: Education Law Center. Retrieved on January 8, 2013, from http://www.elc-pa.org/BestInvestment_Full_Report_6.27.11.pdf.

participate. This is critical for our Native youth, who have high school graduation rates far lower than their non-Native peers.

Administration on Aging

Provide \$30 million for Parts A (Grants for Native Americans) and B (Grants for Native Hawaiians) of the Older Americans Act.—Programs under Title VI of the Older Americans Act are the primary vehicle for providing nutrition and other direct supportive services to American Indian, Alaska Native, and Native Hawaiian elders. Approximately two-thirds of the Part A and Part B grants to tribes or consortia of tribes are for less than \$100,000. This funding level is expected to provide services for a minimum of 50 elders for an entire year. Yet, those tribes receiving \$100,000 typically serve between 200 and 300 elders. As such, many tribes are unable to meet the five-days-a-week meal requirement because of insufficient funding and are serving congregate meals only two or three days per week. Some Title VI programs are forced to close for a number of days each week, unable to provide basic services such as transportation, information and referral services, legal assistance, ombudsman, respite or adult day care, home visits, homemaker services, or home health aide services. Rapidly increasing transportation costs also severely limit Title VI service providers' ability to deliver meals and related supportive services to home-bound Native elders at the current funding level. This funding should be significantly increased so that Native elders receive the care that they deserve.

Provide \$8.3 million for the Native American Caregiver Support Program administered by the Administration on Aging and create a line-item for training for tribal recipients.—The Native American Caregiver Support Program under Part C of the OAA assists American Indian, Alaska Native, and Native Hawaiian families caring for older relatives with chronic illnesses. The grant program offers many services that meet caregivers' needs, including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services. However, this program cannot be effective if it is not adequately funded. It should be funded at \$8.3 million, with sufficient resources also allocated to address historically unmet tribal training needs.

Create a tribal set-aside of \$2 million under Subtitle B of Title VII.—Subtitle B of Title VII of the Older Americans Act authorizes a program for tribes, public agencies, or non-profit organizations serving Native elders to assist in prioritizing issues concerning elder rights and to carry out related activities. While States have been funded at more than \$20 million per year under this program, tribes have never received appropriations for this purpose. Further, tribes have no additional source of mandatory Federal funding for elder protection activities. As such, a \$2 million tribal set-aside should be created under Subtitle B to ensure that tribes have access to such funds at a comparable level to States.

Provide \$3 million for national minority aging organizations to build the capacity of community-based organizations to better serve Native seniors.—Language and cultural barriers severely restrict Native elder access to Federal programs for which they are eligible. Typically, these senior Americans have limited access to and participation in programs such as Social Security, Medicare, and Medicaid. Funding is needed to build capacity for tribal, minority, and other community-based aging organizations to serve Native elders and enroll them in programs to which they are entitled. These efforts could include training tribal staff on expanding Native elders' access to Medicare, Medicaid, housing, congregate meals, and veteran benefits. Efforts could also include working with tribal leaders to leverage existing funds and programs to sustain support for elders. This funding is essential to strengthening local organizations in serving seniors.

National Institutes of Health

Though NCAI is not requesting additional funding for the National Institutes of Health (NIH), we would like to protect current funding levels and highlight the significant negative impact the sequestration will have on many tribal governments and associate research and development projects. Of the major research institutes, the NIH stands to take the greatest hit in terms of total dollars lost at nearly \$2.4 billion. This could severely constrain research on diseases that cost tribal communities millions of dollars each year to treat, including: diabetes, cancer, and heart disease, amongst so many others. It will also affect the number of grants NIH awards each year, which may affect Native-focused funding mechanisms like the Native American Research Centers for Health (NARCH) funded by NIH. NCAI requests that the subcommittee work to protect research for and with tribal communities as these projects continue to inform policymaking decisions and highlight best practices for tribal programs and initiatives.

CONCLUSION

Thank you for your consideration of this testimony. For more information, please contact Amber Ebarb, NCAI Budget and Policy Analyst, at aebarb@ncai.org, Katie Jones, NCAI Legislative Associate, at kjones@ncai.org, Brian Howard, NCAI Legislative Associate, at bhoward@ncai.org, Gerald Kaquatosh, NCAI fellow at gkaquatosh@ncai.org, and Terra Branson, NCAI Legislative Associate, at tbranson@ncai.org.

PREPARED STATEMENT OF THE NATIONAL COUNCIL FOR DIVERSITY IN THE HEALTH PROFESSIONS

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) \$300 million for the Title VII Health Professions Training Programs, including:
 - \$33.6 million for the Minority Centers of Excellence.
 - \$35.6 million for the Health Careers Opportunity Program.
-

Mr. Chairman and members of the subcommittee, thank you for the opportunity to present my views before you today. I am Dr. Wanda Lipscomb, President of the National Council for Diversity in the Health Professions (NCDHP) and the Director of the Center of Excellence for Culture Diversity in Medical Education at Michigan State University. NCDHP, established in 2006, is a consortium of our Nation's majority and minority institutions that once house the Health Resources and Services (HRSA) Minority Centers of Excellence (COE) and Health Careers Opportunities Programs (HCOP) when there was more funding. These institutions are committed to diversity in the health professions. In my professional life, I have seen firsthand the importance of health professions institutions promoting diversity and the Title VII Health Professions Training programs.

Mr. Chairman, time and time again, you have encouraged your colleagues and the rest of us to take a look at our Nation and evaluate our needs over the next 10 years. I want to say that minority health professional institutions and the Title VII Health Professionals Training programs address a critical national need. Persistent and severe staffing shortages exist in a number of the health professions, and chronic shortages exist for all of the health professions in our Nation's most medically underserved communities. Furthermore, our Nation's health professions workforce does not accurately reflect the racial composition of our population. For example while blacks represent approximately 15 percent of the U.S. population, only 2–3 percent of the Nation's health professions workforce is black. Mr. Chairman, I would like to share with you how your committee can help NCDHP continue our efforts to help provide quality health professionals and close our Nation's health disparity gap.

There is a well established link between health disparities and a lack of access to competent healthcare in medically underserved areas. As a result, it is imperative that the Federal Government continue its commitment to minority health profession institutions and minority health professional training programs to continue to produce healthcare professionals committed to addressing this unmet need.

An October 2006 study by the Health Resources and Services Administration (HRSA), entitled "The Rationale for Diversity in the Health Professions: A Review of the Evidence" found that minority health professionals serve minority and other medically underserved populations at higher rates than non-minority professionals. The report also showed that; minority populations tend to receive better care from practitioners who represent their own race or ethnicity, and non-English speaking patients experience better care, greater comprehension, and greater likelihood of keeping follow-up appointments when they see a practitioner who speaks their language. Studies have also demonstrated that when minorities are trained in minority health profession institutions, they are significantly more likely to: 1) serve in rural and urban medically underserved areas, 2) provide care for minorities and 3) treat low-income patients.

As you are aware, Title VII Health Professions Training programs are focused on improving the quality, geographic distribution and diversity of the healthcare workforce in order to continue eliminating disparities in our Nation's healthcare system. These programs provide training for students to practice in underserved areas, cultivate interactions with faculty role models who serve in underserved areas, and provide placement and recruitment services to encourage students to work in these areas. Health professionals who spend part of their training providing care for the

underserved are up to 10 times more likely to practice in underserved areas after graduation or program completion.

Institutions that cultivate minority health professionals, like the NCDHP members, have been particularly hard-hit as a result of the cuts to the Title VII Health Profession Training programs in fiscal year 2006, fiscal year 2007, and fiscal year 2008. Given their historic mission to provide academic opportunities for minority and financially disadvantaged students, and healthcare to minority and financially disadvantaged patients, minority health professions institutions operate on narrow margins. The cuts to the Title VII Health Professions Training programs amount to a loss of core funding at these institutions and have been financially devastating. We have been pleased to see efforts to revitalize both COE and HCOP in recent fiscal years, but it is important to fully fund the programs at least at the fiscal year 2004 level so that more diversity is achieved in our health professions.

Earlier this year with the passage of health reform, the Congress showed the importance of the many of the Title VII programs, including the Minority Centers of Excellence (COE) and Health Careers Opportunities Program (HCOP), by reauthorizing the programs.

Minority Centers of Excellence.—COEs focus on improving student recruitment and performance, improving curricula in cultural competence, facilitating research on minority health issues and training students to provide health services to minority individuals. COEs were first established in recognition of the contribution made by four historically black health professions institutions (the Medical and Dental Institutions at Meharry Medical College; The College of Pharmacy at Xavier University; and the School of Veterinary Medicine at Tuskegee University) to the training of minorities in the health professions. Congress later went on to authorize the establishment of “Hispanic”, “Native American” and “Other” Historically black COEs. For fiscal year 2014, I recommend a funding level of \$24 million for COEs.

Health Careers Opportunity Program (HCOP).—HCOPs provide grants for minority and non-minority health profession institutions to support pipeline, preparatory and recruiting activities that encourage minority and economically disadvantaged students to pursue careers in the health professions. Many HCOPs partner with colleges, high schools, and even elementary schools in order to identify and nurture promising students who demonstrate that they have the talent and potential to become a health professional.

Collectively, the absence of HCOPs will substantially erode the number of minority students who enter the health professions. Over the last three decades, HCOPs have trained approximately 30,000 health professionals including 20,000 doctors, 5,000 dentists and 3,000 public health workers. For fiscal year 2014, I recommend a funding level of \$23 million for HCOPs.

Mr. Chairman, please allow me to express my appreciation to you and the members of this subcommittee. With your continued help and support, NCDHP member institutions and the Title VII Health Professions Training programs can help this country to overcome health and healthcare disparities. Congress must be careful not to eliminate, paralyze or stifle the institutions and programs that have been proven to work. NCDHP seeks to close the ever widening health disparity gap. If this subcommittee will give us the tools, we will continue to work towards the goal of eliminating that disparity everyday.

Thank you, Mr. Chairman.

PREPARED STATEMENT OF THE NATIONAL COUNCIL OF SOCIAL SECURITY
MANAGEMENT ASSOCIATIONS

On behalf of the National Council of Social Security Management Associations (NCSSMA), thank you for the opportunity to submit this testimony regarding the Social Security Administration’s (SSA’s) fiscal year 2014 Appropriation.

NCSSMA is a membership organization of nearly 3,500 SSA managers and supervisors who provide leadership in over 1,200 community-based Field Offices (FOs) and Teleservice Centers (TSCs) throughout the country. We are the front-line service providers for SSA in communities all over the Nation. Since the founding of our organization over forty-four years ago, NCSSMA has considered our top priority to be a stable SSA, which delivers quality and timely community-based service to the American public. We also consider it a top priority to be good stewards of the taxpayers’ monies and the Social Security programs we administer.

We fully support the President’s budget request of \$12.297 billion for SSA’s administrative funding in fiscal year 2014. This request includes a new Program Integrity Administrative Expenses (PIAE) account that will provide new funding in addition to the Limitation on Administrative Expenses (LAE) account dedicated to

program integrity work: medical continuing disability reviews (CDRs) and Supplemental Security Income (SSI) redeterminations.

The PIAE account would provide a reliable stream of mandatory funding dedicated to program integrity efforts. In total, the fiscal year 2014 SSA budget proposal would provide SSA with \$1.5 billion for these cost-saving program integrity workloads. SSA estimates that medical CDRs provide a return-on-investment of more than \$9 for every dollar spent, and for SSI redeterminations it saves \$5 for every dollar spent.

It is critical SSA receives flexible funding for the LAE and PIAE request to respond to the increased requests for assistance from the American public as a result of the aging of the baby boom generation, the economic downturn, and to fulfill our stewardship responsibilities. Without adequate funding, SSA will not be able to provide the high-quality customer service Americans deserve and will be unable to process program integrity workloads, which save taxpayer dollars and reduce the Federal budget and deficit.

SSA TSCs, hearing offices, program service centers (PSCs), disability determination services (DDS), and the over 1,200 FOs are in critical need of adequate resources to address their growing workloads. The fiscal year 2014 budget request would allow SSA to cover inflationary increases, continue efforts to reduce hearings and disability backlogs, increase deficit-reducing program integrity work, and replace some critical staffing losses in SSA's components. It would also help to minimize the closure of additional field offices and improve public service.

SSA is challenged by ever-increasing workloads, very complex programs to administer, and increased program integrity work with diminished staffing and resources. Despite SSA's enormous challenges, SSA's fiscal year 2013 appropriation for administrative funding through the LAE account was about \$370 million below the fiscal year 2012 enacted level, which includes a reduction of \$386 million due to sequestration cuts. The fiscal year 2012 appropriation for administrative funding through the LAE account was approximately \$300 million below the fiscal year 2011 enacted level after rescissions from Carryover Information Technology funds.

This funding level was over \$1 billion below the President's budget request and did not allow SSA to cover inflationary costs for fixed expenses. It resulted in significant reductions in vital services, including a continuation of the hiring freeze in most of SSA; closing all FOs to the public one hour earlier (August 2011 one-half hour and November 2012 an additional one-half hour); closing of all FOs at noon on Wednesdays (effective January 2013); consolidation of 41 FOs and the closure of over 500 remote contact stations since fiscal year 2010; cancellation of plans to open 8 new hearing offices and a new TSC; suspension of mailing annual benefit statements to the public; and postponement of electronic service and programmatic efficiency initiatives.

Public service has deteriorated significantly with increased waiting times as SSA continues to serve a near record number of visitors. Each day, almost 182,000 people visit SSA FOs and more than 445,000 people call for assistance. The waiting time for visitors to date during fiscal year 2013 is nearly 30 percent longer than the same time period in fiscal year 2012. During the first 6 months of fiscal year 2013, over 2.1 million visitors waited more than one hour to be served. The number of visitors leaving without service has increased 10 percent (over 1.2 million visitors).

Despite agency online service initiatives and the reduction of public service hours, 44.9 million visitors were served by FOs in fiscal year 2012, approximately the same as in each of the previous 3 years. SSA's FO busy rate to answer public telephone calls has increased from 7.4 percent in fiscal year 2012 to 14.9 percent (through March 2013). TSCs have also experienced a significant degradation of service. The agent busy rate has increased from 4.6 percent in fiscal year 2012 to 16.8 percent through March 2013. In addition, the time someone waits for their call to be answered has increased by 71 percent.

The need for resources in SSA FOs is critical to provide vital services to the American public. SSA has lost 9,200 employees since the beginning of fiscal year 2011—over 10 percent of its workforce. SSA will have approximately the same number of employees in fiscal year 2013 as it did in fiscal year 2007. FO permanent staffing has gone from 29,481 employees at the end of fiscal year 2010 to 26,298 employees in March 2013—a 10.8 percent decrease. In the last 2 years, more than 600 SSA FOs have lost more than 10 percent of their staff and 16 percent of all SSA FOs have had a net attrition loss of over 20 percent.

Geographic staffing disparities will only increase as ongoing attrition spreads unevenly across the country. This leaves many offices significantly understaffed and without sufficient capacity to address workloads. It is important to note the same SSA FO staff that process medical CDRs and SSI redeterminations, are the same employees who answer telephone calls, take initial claim applications, and develop

and adjudicate benefit claims, which are vital in protecting taxpayer dollars and prevent improper payments before they occur. The SSA fiscal year 2014 budget request would allow SSA to begin replacing critical staffing losses and rebalance service, quality, and stewardship responsibilities.

One of the greatest concerns for SSA is the huge increase in retirement, survivor, dependent, disability, and Supplemental Security Income (SSI) new claims and appeals. Retirement and survivor claims will be over 40 percent higher than in 2007. Initial disability claims have increased by nearly 25 percent and disability hearings have increased by nearly 50 percent since 2007. This increase is driven by the nearly 80 million baby boomers who will be filing for Social Security benefits by 2030 (an average of 10,000 per day) and by the economic downturn.

In fiscal year 2014, SSA expects to handle over 5.4 million retirement, survivors, and Medicare claims; nearly 2.9 million Social Security and SSI initial disability claims; and 278,000 SSI aged claims. Also in fiscal year 2014, SSA will complete approximately 725,000 reconsideration requests, 807,000 hearing requests, 16 million new and replacement Social Security cards, and 1.1 million Medicare prescription drug subsidy applications.

In fiscal year 2012, disability claims receipts exceeded 3 million for the fourth successive year. Since fiscal year 2008, the number of claims pending for a disability medical decision rose from 565,286 to 707,700 in fiscal year 2012—an increase of 142,414, or 25.2 percent. Despite the fact disability receipts have exceeded 3 million for four successive years, the current staffing level for DDSs is 14,064, 2,129 (13.1 percent) below the level at the end of fiscal year 2010. A continued hiring freeze in DDSs for fiscal year 2013 will not allow SSA to complete as many disability claims as received.

SSA was making progress in addressing the enormous backlog of hearings cases, but resource issues have magnified the challenges. After December 2008, when the number of pending hearings rose to 768,540, the backlog was reduced for 19 straight months, to 694,417 in June 2010. However, pending hearings began to increase again and as of the end of March 2013 stood at 833,353 cases. In fiscal year 2012, 849,869 hearing requests were filed, which nearly matched the all-time high for hearing requests in fiscal year 2011, an increase of over 45 percent since fiscal year 2006. The number of disability claims pending is not acceptable to the millions of Americans who depend on Social Security or Supplemental Security Income for their basic income, meeting health care costs, and supporting their families.

Program integrity initiatives save taxpayer dollars and are fiscally prudent in reducing the Federal budget and deficit. To address program integrity, the President's fiscal year 2014 SSA budget request provides a total of \$1.5 billion for the two most cost-effective tools to reduce improper payments—medical CDRs and SSI redeterminations.

If SSA would have received the full \$1.024 billion requested by the President for program integrity initiatives in fiscal year 2013, the estimated program savings over the next 10 years would have been \$8.1 billion. However, as a result of the sequester and the current enacted fiscal year 2013 budget, SSA will not accomplish those levels of program integrity workloads. If the mandatory spending increase proposed in the fiscal year 2014 budget continues through 2023 the savings will be \$37.7 billion.

For millions of Americans, SSA is the face of the Federal Government. Backlogs and delayed services at SSA FOs result in inefficiencies and are a source of customer frustration. Last year, FOs received nearly 4,000 incidents of threat or violence, and there were over 500 incidents in the first three weeks of this year. Untimely services can also be economically disastrous to beneficiaries with disabilities who attempt to return to work and must report their work activity.

Without question, SSA would have used the President's proposed funding for fiscal year 2013 of \$11.76 billion for the LAE account to address the growing workloads facing the agency. Projecting to fiscal year 2014, SSA will require additional funding just to address inflationary costs associated with items such as salaries, employee benefits, rent, and facility security. SSA would also need additional resources to address the backlog of post-eligibility work and medical CDRs.

SSA estimates the effect of sequestration on fiscal year 2013 SSA operations will result in pending levels of initial disability claims rising by over 140,000 claims; applicants may wait two weeks longer for initial disability decisions and nearly a month longer for disability hearing decisions; and staffing losses (attrition without replacement) of over 3,400 more employees are anticipated. It is essential to preserve good service to the American public at SSA. SSA must be properly funded to ensure the efficient, accurate, and expeditious administration of this vital social program.

We realize that the fiscal year 2014 funding level outlined above is significant, particularly in this difficult Federal budget environment. However, Social Security is a key component of America's economic safety net for the aged and disabled and is facing unprecedented challenges. Even with the President's proposed budget, SSA expects an annual growth in their backlog of 2,800 work years. The American public expects and deserves SSA's assistance.

SSA needs sufficient resources to fulfill its stewardship responsibilities, process its core workloads, reduce the hearings backlog and accomplish critical program integrity workloads, which ensure accurate payments, save taxpayer dollars, and is fiscally prudent. We are confident this investment in SSA will benefit our entire Nation.

On behalf of NCSSMA members nationwide, thank you for the opportunity to submit this written testimony. We respectfully ask that you consider our comments, and would appreciate any assistance you can provide in ensuring the American public receives the critical and necessary service they deserve from the Social Security Administration.

PREPARED STATEMENT OF THE NATIONAL FAMILY PLANNING & REPRODUCTIVE
HEALTH ASSOCIATION

Summary.—Requesting \$327 million in funding for fiscal year 2014 for the national family planning program (Title X of the Public Health Service Act).

My name is Clare Coleman; I'm the President & CEO of the National Family Planning & Reproductive Health Association (NFPRHA), a membership association representing the Nation's family planning provider systems. A majority of NFPRHA's more than 500 members receive Federal funding from Medicaid and through Title X of the Public Health Service Act, the only dedicated federally funded family planning program for the low-income and uninsured. These programs are a part of the Nation's public health safety net, and are at the forefront of efforts to reduce rates of unintended pregnancy and improve sexual and reproductive health outcomes.

NFPRHA requests that you make a significant investment in the Title X family planning program in the fiscal year 2014 bill by supporting the President's request and appropriating \$327 million. Title X sustained significant cuts—\$23.6 million—in fiscal years 2011 and 2012, at a time when the need for publicly subsidized health care is growing. As a result of sequestration, it is estimated that the program will sustain an additional 5%–9 percent cut. Cuts to Title X health systems have led to health center hours being cut and staff layoffs—which directly led to a sharp drop in the number of patients seen in the program in 2011, the last year for which Federal data are available.

Title X-funded centers serve more than 5 million low-income women and men annually at nearly 4,400 health centers. Title X services help women and men plan the number and timing of pregnancies, helping to prevent nearly one million pregnancies a year, which would have likely resulted in 432,600 unintended births and 406,200 abortions. In addition to providing contraceptive services and supplies, Title X health centers provide preventive health services, education, and counseling. Title X assists with patient referrals and helps coordinate care for individuals who traditionally have lacked access to routine care. The services provided at publicly funded health centers not only improve public health, they save billions of taxpayer dollars each year. In 2008, publicly funded family planning saved Federal and State governments \$5.1 billion; services provided at Title X-supported centers accounted for \$3.4 billion in such savings in that same year alone. A recent estimate from the Brookings Institution found that expanding publicly funded family planning services would produce taxpayer savings of \$2–\$6 for every dollar spent.

For more than 40 years, Title X has been a critical safety net for those living in under-resourced communities across the country. The \$23.6 million in cuts to Title X in fiscal year 2011 and fiscal year 2012—a 7.4 percent loss of funding—came after the largest growth of patients served by the Title X network in more than a decade, an increase of more than 170,000 women, men, and teens between 2008 and 2010. Unfortunately, the recent funding cuts have reversed this trend, and in just 1 year between 2010 and 2011, the program experienced a decline of more than 200,000 patients.

Today, safety-net providers deliver health care to many in need, and especially those in vulnerable populations, a role that will undoubtedly grow when full ACA coverage expansion begins in 2014. Despite the proven cost savings and public support of Title X, the program is still under extreme pressure. A funding level of \$327 million would help to stabilize systems following the significant damage done by

Federal and State budget cuts over the last few years. This is essential—if we do not stabilize the system now, this network of providers will not be available to serve those in need, including the millions of individuals who will gain health coverage through the ACA and will seek health care in the safety net.

Thank you for the opportunity to testify on the role of Title X in the public health safety net. NFPRHA stands ready to work with you to strengthen America's network of family planning providers and its role in helping to ensure that health care reforms are a success.

PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

Chairman Harkin, Ranking Member Moran, and members of the subcommittee, thank you for allowing the National Head Start Association (NHSA) to submit testimony on behalf of funding for Head Start and Early Head Start in fiscal year 2014 (fiscal year 2014). Head Start centers provide critical early education, health, nutrition, child care, parent engagement and family support services in return for a life-long measurable impact on the low-income children and families who are served. NHSA urges Congress to support robust investment in Head Start centers nationwide in order to provide quality school readiness opportunities for the most at-risk young children and their families—especially as they face greater obstacles today than ever.

NHSA is grateful for the enduring, bipartisan support of Congress and every President for Head Start throughout its 48 year history. We are particularly appreciative of the leadership of this subcommittee, and hope it gives serious consideration to the President's proposal to increase access to high-quality early learning programs. As our Nation's flagship early learning program, we believe Head Start can serve as the model for expansion. In fiscal year 2014, we believe there are important investments that must be made in Head Start and other early learning initiatives. First, however, we urge you to consider our highest priority: restoring services to the children and families across the country we will lose and have lost due to sequestration.

The 5.27 percent cut that all Head Start grantees were directed to make on March 1st has already had disruptive and serious impact. Many programs are already in the process of notifying families that their children no longer have a place in our classrooms and that families will be on their own next school year. Two Indiana programs have resorted to a lottery drawing to figure out which families would be cut from the program.

We certainly do not want to cut children, but due to several years of continued increases to operating costs, there is no budget cushion. During this most recent recession, Head Start and Early Head Start directors have had extreme difficulty maintaining their program size, resulting in the loss of 7,000 Head Start slots even before sequestration took effect. Under sequestration, every program will need to cut services for children and families, and therefore staff, to absorb the reduction. Nationally, the Department of Health and Human Services estimates that sequestration will result in 70,000 fewer children receiving Head Start services. NHSA hopes that Members of this subcommittee will work with their Senate colleagues towards restoration of Head Start cuts in fiscal year 2014.

Once sequestration is repealed we can then turn to the bold plan to dramatically increase access to high quality early learning that President Obama has put forth. The Head Start community sees enormous potential in the President's fiscal year 2014 Budget proposal to expand early learning opportunities for low to middle income children. We also see challenges in the areas of quality, workforce needs, and overall cost that may hinder success. We are prepared to offer specific recommendations to ensure that an expanded system works well for children, families, and our taxpayers.

Specifically, the Head Start community supports the Administration's request for an increase of \$1.6 Billion to Head Start in fiscal year 2014. We propose that within this amount, Head Start and Early Head Start programs are first allowed to address their rising operating costs, and then are able to expand Early Head Start services consistent with the President's proposal. Additionally, we hope the subcommittee will consider our suggestions for an expanded pre-Kindergarten system that could have great impact on our children for generations to come.

Head Start Fixed Costs Continue to Rise

Within the \$1.6 billion request for Head Start and Early Head Start, the President proposes to give current grantees an additional \$200 million to help meet rising operating costs. NHSA proposes that the Administration instead set aside \$419

million to help programs ‘catch up’ from previous years; without full adjustments, centers have been falling behind. Even before sequestration, the cost of serving families has risen at a much faster pace than any increase in funding. All grantees have experienced a rapid increase in their fixed costs, including maintenance, fuel, transportation, and health insurance. In some areas, rent on facilities alone has gone up between 5–10 percent. It is an enormous task to keep costs low and still maintain Head Start’s high-quality comprehensive model. Prior to the 2012–2013 school year, programs had already laid off staff, closed facilities and consolidated programs to cut costs, and have leaned more than ever on community partners to help provide health, employment, and other services required by the comprehensive model.

Increases in fuel costs have impacted programs greatly, especially in rural areas where transportation to and from the center is critical for families in a sprawling service area. Some rural southern programs report that fuel costs have gone up over 64%—affecting transportation, waste removal, and food prices. Deferred maintenance of Head Start centers poses its challenges as well; centers operating in older facilities hope the roof will hold out one more year, or that the playground equipment will remain solid and safe. Regardless, the centers are judged by frequent monitors who have the ability to demand change when they see a potential hazard—with the additional funds being requested, Head Start directors could do more to prevent potential safety hazards.

Finally, the significant continuous rise in the cost of health insurance has been particularly detrimental for programs across the country. Last year in Louisiana, the Iberville Parish Council Head Start, which serves 360 children and employs 61 teachers and staff at 6 centers, struggled to make ends meet because of rising health insurance and other costs. Ultimately, the Parish Council voted to relinquish control of the program entirely and turn it over to the Federal Government rather than tell families they could not serve their children because they could not afford to continue subsidizing the increasing costs. By prioritizing grantees’ ability to meet these costs in fiscal year 2014, the subcommittee will ensure that current centers can provide a consistently high-quality level of service to their local children and families.

Expanded Access to Early Head Start

NHSA strongly supports the President’s vision of increasing investments in Early Head Start (EHS). The available research on child brain development clearly shows the effectiveness of high-quality early interventions. However, high-quality infant care options are extremely limited, especially for low-income families. Early Head Start is only able to serve a scant 4 percent of eligible infants, about 110,000 slots. In order to really fully address the continuum, we need to invest in access to quality programs, and the President’s proposal would nearly double the available slots in EHS.

The President proposes expanding access to programs that are at the EHS level of quality, but executed through partnerships with local child care (CC) providers. NHSA applauds the Administrations’ effort to improve both the lack of access to and the overall quality of care for infants and toddlers. However, policy makers must understand that the missions of CC and EHS are inherently different—and the structure of these partnerships must be carefully considered. We propose that a multitude of flexible expansion options be eligible, including contracts between EHS–CC/Family Child Care (FCC), expansion of existing EHS center-based/home-based services, and allowing EHS providers to offer training and technical assistance bring area CC providers up to EHS standards. Further, innovative program proposals should be encouraged by allowing exemptions or a significant “hold harmless” period from the Designation Renewal System.

The President’s proposal also calls for the conversion of current 4 year-old Head Start slots into Head Start and Early Head Start slots for children birth to age four. We believe this decision should be based on community capacity and need, as opposed to a unilateral policy decision made in Washington, DC. Head Start should be allowed to continue serving both three and 4 year-olds while expanding, rather than converting, Early Head Start slots in order to truly serve the 0–5 continuum. It must also be recognized that the conversion of Head Start slots into Early Head Start slots includes significant additional cost, time, and challenges, including different staff ratios, facility requirements, and stark differences between the credentials required for Early Head Start versus Head Start teachers. One program in California that recently went through the slot conversion process informed NHSA that they converted 166 Head Start slots into an equivalent of 70 Early Head Start slots. This is in line with the national conversion experience.

We hope this subcommittee will show its support for current initiatives to allow grantees to restructure along a birth-to-five continuum. On February 4th, 2013, the

Office of Head Start announced the first pilot funding for birth to five projects in Detroit, Baltimore, Jersey City, Washington, DC, and Mississippi's Sunflower County. Each community had been included in the first cohort of Designation Renewal System recompetitions, and the Office of Head Start saw an opportunity to try a different configuration. The grants are meant to encourage applicants to develop comprehensive, flexible, seamless birth-to-five programs which incorporate both Head Start and Early Head Start funding. By providing a streamlined grant to create a tailored local approach, these birth to five pilots will serve as the model for a continuum of comprehensive services that meet the diverse and challenging needs of families in these communities. We hope the subcommittee will recognize the value of this approach and support expansion of these models.

Pre-Kindergarten Expansion

The central component of the President's proposal is the creation of a pre-kindergarten program that seeks to partner with and leverage State investments so they might take over responsibility for Pre-K within 10 years. While this long-term goal is admirable, there are several challenges in the areas of quality, workforce pipeline, and overall cost that may hinder success. We encourage careful consideration of the following six suggestions for the proposed expansion of State pre-kindergarten programs over the next 10 years.

First and foremost, we hope Congress will ensure the creation of a diverse and mixed delivery system, rather than creating a duplicative system through the school system. Such a strategy would utilize existing providers in a community to ensure faster scaling, better quality, and locally-appropriate programs. From the Head Start perspective, this is the most cost-effective option that allows communities to determine what its needs are, and which providers within that community can serve these children and families best.

Further we sincerely hope that this subcommittee will help reiterate the importance of two critical components of the Head Start model: parent engagement and comprehensive services. New programs under this expansion should be required to implement clear, meaningful, evidence-based parent and family engagement standards and practices for participating States and classrooms. These components work. A study released by the National Bureau of Economic Research shows that Head Start parents are more actively engaged in their children's academic careers long after the child has entered kindergarten, a key ingredient of a learning environment that leads to future success.¹ The Baltimore Education Research Consortium (BERC) released findings in March 2012 related to chronic absenteeism in Kindergarten—which studies have shown to relate to poorer overall academic achievement as late as 5th Grade. Pre-school-aged children are completely reliant on their parents to prioritize attendance at this stage of life. BERC's research shows that students who had attended Head Start showed the highest attendance rates in kindergarten and the lowest level of chronic absence in first through third grades.²

We also hope that a new expanded pre-k system will include support for providing the comprehensive health and development services for the children and families who need them. Head Start families with their increased health literacy also show immediate health care benefits, including lower Medicaid costs—on average \$232 per family. The program has also reduced mortality rates from preventable conditions for 5-to 9-year olds by as much as 50 percent.³ Studies have shown that the program reduces health care costs for employers and individuals because Head Start children are less obese,⁴ 8 percent more likely to be immunized,⁵ and 19 to 25 percent less likely to smoke as an adult.⁶

Head Start Works

Looking forward, we hope this subcommittee will continue to support Head Start as a high-yield investment. Studies show that for every one dollar invested in a

¹National Bureau of Economic Research. (2011, December). Children's Schooling and Parents' Investment in Children: Evidence from the Head Start Impact Study (Working Paper No. 17704). Cambridge, MA: A. Gelber & A. Isen.

²Baltimore Education Research Consortium (2012, March). Early Elementary Performance and Attendance in Baltimore City Schools' Pre-Kindergarten and Kindergarten. Baltimore, MD: F. Connelly & Olson, L.

³Ludwig, J. and Phillips, D. (2007) Does Head Start improve children's life chances? Evidence from a regression discontinuity design. *The Quarterly Journal of Economics*, 122 (1): 159–208.

⁴Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06-WG01.

⁵Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review*, 85 (3): 360.

⁶Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587–602.

Head Start child, society earns at least \$7 back through increased earnings, employment, and family stability;⁷ as well as decreased welfare dependency,⁸ health care costs,⁹ crime costs,¹⁰ grade retention,¹¹ and special education.¹²

Head Start saves tax dollars by decreasing the need for children to receive special education services in elementary schools.¹³ Data analysis of a recent Montgomery County Public Schools evaluation found that a MCPS child receiving full-day Head Start services when in Kindergarten requires 62 percent fewer special education services, and saves taxpayers \$10,100 per child annually.¹⁴ States can save \$29,000 per year for each person that they don't need to incarcerate because Head Start children are 12 percent less likely to have been charged with a crime.¹⁵ These non-test-score findings help illustrate the long-term viability of the program—today, more than 27 million Head Start graduates are working every day in our communities to make our country and our economy strong.

Again, the Head Start community understands the budgetary pressures the Federal Government is facing and is very grateful for the commitment shown by Congress and the President to keep early learning, and Head Start in particular, as a priority. The research shows that the “achievement gap” is apparent as early as the age of 18 months—we will spend substantially more downstream if these same young people are not prepared to graduate high-school, attend college and lead prosperous lives. We urge the subcommittee to restore the drastic cuts to Head Start and Early Head Start, and support increased access to high-quality early learning programs for children along the 0–5 continuum. In doing so, together we will ensure that we have a stable and prosperous workforce for generations to come. Thank you for your time and consideration.

PREPARED STATEMENT OF THE NATIONAL HEALTH COUNCIL

Dear Chairman Harkin and Ranking Member Moran: On behalf of the Nation's leading patient advocacy organizations, thank you for the opportunity to submit testimony on the significance of funding for Federal health research agencies and other programs that are designed to improve the health of our Nation. As work begins on the fiscal year 2014 Labor-HHS appropriations bill, the NHC urges the subcommittee to maximize funding for essential health programs, including those at the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), and the Agency for Healthcare Research and Quality (AHRQ). We urge Congress to refrain from shying

⁷Ludwig, J. and Phillips, D. (2007). The Benefits and Costs of Head Start. *Social Policy Report*. 21 (3: 4); Deming, D. (2009). Early childhood intervention and life-cycle skill development: Evidence from Head Start. *American Economic Journal: Applied Economics*, 1(3): 111–134; Meier, J. (2003, June 20). Interim Report. Kindergarten Readiness Study: Head Start Success. Preschool Service Department, San Bernardino County, California; Deming, D. (2009, July). Early childhood intervention and life-cycle skill development: Evidence from Head Start, p. 112.

⁸Meier, J. (2003, June 20). Kindergarten Readiness Study: Head Start Success. Interim Report. Preschool Services Department of San Bernardino County.

⁹Frisvold, D. (2006, February). Head Start participation and childhood obesity. Vanderbilt University Working Paper No. 06–WG01; Currie, J. and Thomas, D. (1995, June). Does Head Start Make a Difference? *The American Economic Review*, 85 (3): 360; Anderson, K.H., Foster, J.E., & Frisvold, D.E. (2009). Investing in health: The long-term impact of Head Start on smoking. *Economic Inquiry*, 48 (3), 587–602.

¹⁰Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. *American Economic Review*, 92 (4): 999–1012.

¹¹Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows.; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-Term Effects of Head Start. *American Economic Review*, 92 (4): 999–1012.

¹²NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). *Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services*. Office of Shared Accountability, Montgomery County Public Schools.

¹³Barnett, W. (2002, September 13). The Battle Over Head Start: What the Research Shows. Presentation at a Science and Public Policy Briefing Sponsored by the Federation of Behavioral, Psychological, and Cognitive Sciences.

¹⁴NHSA Public Policy and Research Department analysis of data from a Montgomery County Public Schools evaluation. See Zhao, H. & Modarresi, S. (2010, April). *Evaluating lasting effects of full-day prekindergarten program on school readiness, academic performance, and special education services*. Office of Shared Accountability, Montgomery County Public Schools.

¹⁵Reuters. (2009, March). Cost of locking up Americans too high: Pew study; Garces, E., Thomas, D. and Currie, J. (2002, September). Longer-term effects of Head Start. *American Economic Review*, 92 (4): 999–1012.

away from its longstanding commitment to serve people with chronic conditions, the individuals who use our health system on a daily basis.

The National Health Council (NHC) is the only organization of its kind that brings together all segments of the health care community to provide a united voice for the more than 133 million people living with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations and businesses, its core membership includes the Nation's leading patient advocacy organizations, which control its governance. Other members include professional societies and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, biotechnology, and insurance companies.

The NHC fully appreciates the challenging fiscal environment facing the country and your important role in guiding our Nation through these complex and difficult times. The NHC recognizes that Federal resources must be carefully allocated so as to ensure that such investments produce the greatest good for the American people.

In turn, let us not forget that Federal support of health programs at HHS is moving us closer to making the impossible possible—saving medical expenses through effective prevention efforts and new treatments, and saving lives in the process.

The NHC and its member patient organizations cannot overstate that Federal support of medical research, prevention programs, and health care delivery is vital to people living with chronic diseases and disabilities. As we depict in Figure 1, these services should not be considered in isolation, but rather serve as essential building blocks toward strengthening the collective health care system.

Investment in biomedical research is leading the discovery of biomarkers—physical signs or biological substances that indicate the presence of conditions such as osteoarthritis, one of the leading causes of disability in the elderly and the most common type of arthritis in the U.S., usually affecting middle-aged and older people. This type of research will advance our understanding of disease progression and earlier detection and aid in expediting clinical trials on novel treatments.

Funds to pay for the study of rare or less common diseases will help to greatly improve our understanding of human health—and the more common conditions that burden us all. For example, research on alpha-1 antitrypsin deficiency—a disease affecting no more than 100,000 people—fueled new areas of investigation on COPD, a respiratory condition found in more than 12 million individuals.

The path to discovery supported by the Federal Government can result in cutting-edge, cost-effective programs. A widely-regarded NIH clinical trial on diabetes and subsequent translational research found that modest weight loss helped prevent type 2 diabetes for 58 percent of participants and positive results could be obtained for less than \$300 per person per year. These findings led to the creation of CDC's National Diabetes Prevention Program, which serves individuals with prediabetes in local communities across the country.

Research, prevention efforts, and programs that provide access to services and treatments each contribute importantly to enabling patients to manage their health. As baby boomers age, the prevalence of and deaths from diseases such as Alzheimer's and heart disease are projected to increase. Clearly, now is not the time to decrease our Nation's investment in research that holds the key to the prevention, treatment, and cure of America's leading and most costly causes of death.

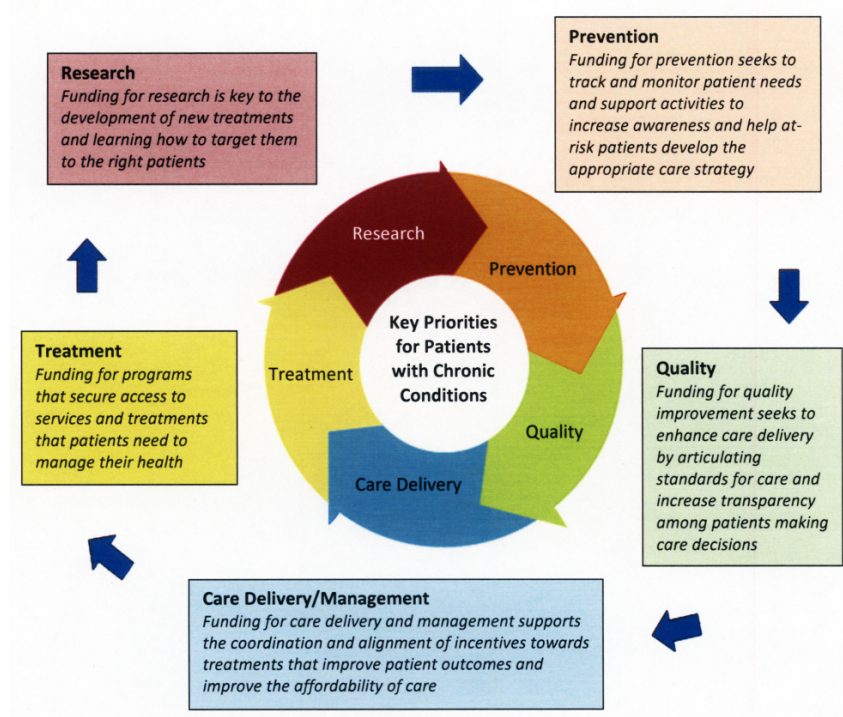
The NHC would be happy to provide the subcommittee with numerous personal patient stories that demonstrate why appropriate funding of research, prevention, and health delivery programs is crucial to the millions of men, women, and children in this country living with chronic diseases and disabilities. We understand the difficulty you face in reaching consensus on a funding level that balances the needs of our country with the needs of people with few or possibly no treatment options.

But how do you place a cost figure on people like Debra—a woman diagnosed with chronic kidney disease who, after many years of dialysis, underwent a successful kidney transplant that was made possible because of advancements based on federally funded research? She was able to give back to society as a volunteer at Walter Reed Army Medical Center, helping others confronted with organ failure to deal with the changes in their lives and remain positive.

If we fail to take aggressive and deliberate action now to appropriately fund essential health programs, we will pay a terrible cost later—both in terms of health care expenditures and human lives.

The NHC appreciates the opportunity to submit this written testimony to the subcommittee. We understand that you face many hard decisions and again urge you to maximize funding for health programs that benefit people with chronic diseases and disabilities so that patients will be able to live longer, healthier, and more productive lives.

Figure 1. Funding the Continuum of Care for Patients with Chronic Diseases and Disabilities



PREPARED STATEMENT OF THE NATIONAL INDIAN CHILD WELFARE ASSOCIATION

The National Indian Child Welfare Association (NICWA) is a national American Indian/Alaska Native (AI/AN) organization with over 25 years of experience in providing leadership in support of and analysis of public policy that affects AI/AN children and families. NICWA regularly provides community and program development technical assistance to tribal communities regarding the development of effective services for this population. Our primary focus will be on Department of Health and Human Service programs serving AI/AN children and families. We thank the subcommittee for its efforts to honor the Federal trust responsibility and provide necessary resources to meet the unique needs of tribal children and families.

DHHS TITLE IV—B SUBPART 2: PROMOTING SAFE AND STABLE FAMILIES (PSSF)

Request.—Increase fiscal year 2014 appropriations for the discretionary component of this program to \$75 million (fiscal year 2012 enacted \$63 million). This would increase the number of tribes eligible (currently 121) and increase allocations for eligible Indian tribes. Only tribes who are eligible for grants of \$10,000 or more under the statutory formula are eligible to apply.

Data and background to justify requests

PSSF is one of only a few Federal funding streams that can be used for services that prevent out-of-home placement and work to strengthen families where either the children are at risk of being placed or have been placed. These services form the foundation of all tribal child welfare programs and are critical to successful outcomes for their children and families. The funds are typically used to establish and operate integrated, preventive family preservation services and family support serv-

ices for families at risk and/or in crisis. This funding is a particularly valuable tool for tribal child welfare because family preservation and family reunification work aligns with traditional American Indian and Alaska Native (AI/AN) cultures and practices. Mainstream approaches to child welfare, which can often be in conflict with AI/AN ways of being and healing, often result in disproportionate placement of AI/AN children in State systems.

Anecdotes of successes of the Federal investment in tribal programs

From Tlingit & Haida Tribes.—Our Preserving Native Families (PNF)/ICWA department received a phone call from the Office of Children's Services (OCS) regarding concerns for two children and explained their concerns regarding the mother's behavior. OCS was preparing to go into the home for an initial investigation.

Our office did some research and learned that the mother was a TANF client. One of our supervisors made a call to our TANF program and asked if they would consider using a new assessment tool, created by the PNF department, to determine if the woman might be at risk for OCS involvement. The TANF worker agreed and based on the score, which was high, the TANF child welfare worker was able to engage the woman in PNF services quickly. OCS, pleased that PNF services were being offered, met with the woman who reported about the PNF services she was involved with. OCS determined that her children were safe and that the mother was actively engaging in prevention services with PNF. This mother only needed someone to reach out to her; she was in need of help, but did not know how to ask. This story is successful for two reasons; departments collaborated and a tribal family remains together today. It is Title IV-B Subpart 2 combined with BIA ICWA Title II funding that made this possible by providing the base levels of funding for Tlingit & Haida's PNF/ICWA department.

DHHS CHILD ABUSE PREVENTION AND TREATMENT ACT (CAPTA) CHILD ABUSE
DISCRETIONARY ACTIVITIES

Request.—Request \$10 million increase in appropriations for this discretionary grant program to account for the inclusion of tribes as eligible applicants; include in the appropriations reporting language requirements for better outreach to tribes and AI/AN service providers and that funding be provided for tribes and AI/AN service providers.

Data and background to justify requests

The CAPTA discretionary fund supports a variety of activities, including research and demonstration projects that study the causes, prevention, identification, assessment and treatment of child abuse and neglect. There is little information on the causes and/or risk factors for abuse and neglect specific to AI/AN families.¹ Similarly, interventions and assessments that take into account cultural considerations for AI/AN children are lacking.² This is largely due to the fact that tribal communities are under resourced and therefore unable to engage in evidence-based practices and practice-based evidence because there is no national focus on this issue.

CAPTA discretionary funds can fill this gap by providing tribes the necessary monies to support their capacity for research and development in the area of child abuse and neglect prevention, identification, assessment and treatment. Though the CAPTA Reauthorization Act of 2010 provides tribes with new funding opportunities under the research and demonstration discretionary grant programs, still more can be done to increase equitable tribal access to this important source of Federal funding.

Since the inception of these discretionary grant programs, tribal children's interests and issues have been given almost no focus in any of the grant awards. This lag in attention to tribal children's needs has created a vacuum in which accurate data, development, and testing of more effective practices in the prevention of child abuse and the protection and treatment of AI/AN children has not occurred. An accurate and culturally competent understanding of the specific risk factors and needs of AI/AN families and communities ensures that programs that work with AI/AN

¹ Bigfoot, D.S., Crofoot, T., Cross, T.L., Fox, K., Hicks, S., et al. (2005). Impacts of Child Maltreatment in Indian Country: Preserving the Seventh Generation through Policies, Programs, and Funding Streams: A Report for BIA. Portland, OR: National Indian Child Welfare Association.

² Bigfoot, D.S., Crofoot, T., Cross, T.L., Fox, K., Hicks, S., et al. (2005). Impacts of Child Maltreatment in Indian Country: Preserving the Seventh Generation through Policies, Programs, and Funding Streams: A Report for BIA. Portland, OR: National Indian Child Welfare Association.

children will be the most effective and efficient. Appropriations reporting language that increases outreach and encourages funding of tribal programs coupled with an overall increase in appropriations will begin to fill this vacuum and improve services for AI/AN children nationwide.

SAMHSA PROGRAMS OF REGIONAL AND NATIONAL SIGNIFICANCE (CIRCLES OF CARE
CHILDREN'S MENTAL HEALTH GRANT PROGRAM)

Request.—Continue fiscal year 2014 appropriation for Programs of Regional and National Significance budget category at fiscal year 2012 level of \$286 million. Funds for the Circles of Care program come out of this budget category (typically \$3 million per year).

Data and background to justify requests

The Circles of Care Grant Program is the only children's mental health funding program exclusively available to tribes. It is the only source of Federal funding that specifically supports the development of culturally competent children's mental health service delivery models in tribal communities, effective systemic reform and capacity building are otherwise impossible due to lack of designated funding.

The need for continued and increased Circles of Care funding is evidenced in available mental health data and the demonstrated and measured effectiveness of the program. For example, AI/AN youth experience post-traumatic stress disorder at higher rate than the national average,³ struggle with alcohol use disorders at a higher rate than the general youth population,⁴ and have had the highest lifetime major depressive episode prevalence and the highest prevalence of a major depressive episode in the last year when compared to all other youth populations.⁵

To date, Circles of Care has enabled 38 tribal grantee communities to develop culturally competent, community-based children's mental service delivery models. Circles of Care yields measurable long-term positive outcomes. These grants have significantly increased tribal community awareness of the issues that impact their children's mental health, facilitated community ownership and responses, and helped tribes to develop capacity through leveraging of tribal funds and creating new partnerships. Of those tribes that have graduated from the Circles of Care program, nearly 1/3 have obtained direct funding through the Child Mental Health Initiative (CMHI) program, otherwise known as Systems of Care; others have been able to partner with other CMHI grantees to implement their models, and remaining graduated sites have secured other resources to implement their models to their best ability.

SAMHSA SYSTEMS OF CARE CHILDREN'S MENTAL HEALTH GRANT PROGRAM

Request.—Continue to fund this program in fiscal year 2014 at the fiscal year 2012 level of \$117 million. This competitive grant program allows eligible States, local governments and tribes to apply for and administer a children's mental health services program (tribes at \$5–6 million per year).

Data and background to justify requests

The current six-year tribal grantees are engaging local communities, youth, families, and private and public partners in collaborative partnerships to build sustainable children's mental health programs and services. National aggregate data on six-year Systems of Care programs illustrate the success and continued need for Systems of Care program funding: 1) emotional and behavioral problems were reduced or remained stable for 89 percent of children and youth with co-occurring mental health and substance abuse diagnoses; 2) school performance improved or remained the same for 75 percent of children and youth served by the grant communities; and 3) almost 91 percent of children and youth with a history of suicide at-

³Cooper, J.L., Masi, R., Dababnah, S., Aratani, Y., and Knitzer, K. (2007). Strengthening Policy to Support Children, Youth, and Families Who Experience Trauma. New York, NY: National Center for Children in Poverty, Mailman School of Public Health, Columbia University. Retrieved from http://www.nccp.org/publications/pub_737.html.

⁴Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA) (2007, January 19). Substance use and substance use disorders among American Indians and Alaska Natives. The National Survey on Drug Use and Health Report. Retrieved from <http://oas.samhsa.gov/2k7/AmIndians/AmIndians.cfm>.

⁵Urban Indian Health Institute, Seattle Indian Health Board (2012). Addressing Depression Among American Indians and Alaska Natives: A Literature Review. Seattle, WA: Urban Indian Health Institute. Retrieved from <http://www.uihi.org/wp-content/uploads/2012/08/Depression-Environmental-Scan-All-Sections-2012-08-21-ES-FINAL.pdf>.

tempts or suicidal ideation improved or remained stable.⁶ Considering these positive outcomes and the behavioral health needs of tribal communities, continued six-year Systems of Care program funding is vital to tribes and their ability to design and implement successful children's mental health programs, particularly because tribes remain ineligible for direct access to the Mental Health Block Grant and Medicaid funding.

Anecdotes of successes of the Federal investment in tribal programs

From Cherokee Nation.—Cherokee Nation's Behavioral Health Services had been working on various children's initiatives for 8 years prior to receiving the SAMHSA Systems of Care (SOC) Expansion Planning Grant last year. During its 1 year as a SOC Expansion Planning grantee, Cherokee Nation accomplished more success in this arena than ever before. The funds were used as seed money to plan and lay the foundation for expanding and sustaining children's mental health. One concrete result of receiving these funds was Cherokee Nation's ability to assess and begin to revamp its children's mental health billing system. None of this could have been possible without the technical assistance (TA) resources provided, the guiding SOC philosophy, and systems-wide approach that created space for the larger Cherokee Nation and community coalitions to engage actively and benefit from the planning process and outcome. Cherokee Nation has since secured funding to begin implementing pieces of the strategic plan developed per the SOC Expansion Planning funding.

For more information regarding this testimony, please contact NICWA Government Affairs Director David Simmons at desimmons@nicwa.org.

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation is pleased to submit testimony for the written record in support of the Centers for Disease Control and Prevention Chronic Kidney Disease Program. We respectfully request \$2.2 million be provided for fiscal year 2014.

End Stage Renal Disease (ESRD), which requires dialysis or transplantation for survival, is the only disease-specific coverage under Medicare, regardless of age or other disability. At the end of 2010, the number of Americans with ESRD totaled more than 594,000, including 415,000 dialysis patients and almost 180,000 kidney transplant recipients. Complicating the cost and human toll is the fact that chronic kidney disease (CKD) is a disease multiplier; patients are very likely to be diagnosed with diabetes, cardiovascular disease, or hypertension (40 percent of ESRD patients had a diagnosis of diabetes). In 2010, CKD was present in 8.4 percent of Medicare beneficiaries but was responsible for 17 percent of Medicare expenditures.

Despite this tremendous social and economic impact, no national public health program focusing on early detection and treatment existed until fiscal year 2006, when Congress provided \$1.8 million to initiate a Chronic Kidney Disease Program at the Centers for Disease Control and Prevention (CDC). Congressional interest regarding kidney disease education and awareness also is found in Sec. 152 of the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, Public Law 110-275), which directed the Secretary to establish pilot projects to increase screening for CKD and enhance surveillance systems to better assess the prevalence and incidence of CKD. Cost-effective treatments exist to potentially slow progression of kidney disease and prevent its complications, but only if individuals are diagnosed before the latter stages of CKD.

The CDC program is designed to identify members of populations at high risk for CKD, develop community-based approaches for improving detection and control, and educate health professionals about best practices for early detection and treatment. The President's budget request includes provisions calling for the continuation of the program, however, does not include a line item. The National Kidney Foundation respectfully urges the Committee to maintain line-item funding for the Chronic Kidney Disease Program for fiscal year 2014. The specific inclusion of a line item will ensure the program is appropriately supported and the continuation of these important activities. Continued support will benefit kidney patients and Americans who are at risk for kidney disease, advance the objectives of Healthy People 2020

⁶Duclos, C.W., Phillips, M. & LeMaster, Public Law (2004). Outcomes and Accomplishment of the circles of Care Planning Efforts. American Indian Alaska Native Mental Health Research Journal. Retrieved from [http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2011/11\(2\)_Duclos_Outcomes_and_Accomplishments_121-138.pdf](http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/CAIANH/journal/Documents/Volume%2011/11(2)_Duclos_Outcomes_and_Accomplishments_121-138.pdf).

and the National Strategy for Quality Improvement in Health Care, and fulfill the mandate created by Sec. 152 of MIPPA.

The prevalence of CKD in the United States is higher than a decade earlier. This is partly due to the increasing prevalence of the related diseases of diabetes and hypertension. It is estimated that CKD affects 26 million adult Americans¹ and that the number of individuals in this country with CKD who will have progressed to kidney failure, requiring chronic dialysis treatments or a kidney transplant to survive, will grow to 712,290 by 2015.² Kidney disease is the 9th leading cause of death in the U.S. Furthermore, a task force of the American Heart Association noted that decreased kidney function has consistently been found to be an independent risk factor for cardiovascular disease (CVD) outcomes and all-cause mortality and that the increased risk is present with even mild reduction in kidney function.³ Therefore addressing CKD is a way to achieve one of the priorities in the National Strategy for Quality Improvement in Health Care: Promoting the Most Effective Prevention and Treatment of the Leading Causes of Mortality, Starting with Cardiovascular Disease.

CKD is often asymptomatic, a "silent disease," especially in the early stages. Therefore, it goes undetected without laboratory testing. In fact, some people remain undiagnosed until they have reached CKD Stage 5 and literally begin dialysis within days. However, early identification and treatment can slow the progression of kidney disease, delay complications, and prevent or delay kidney failure. Accordingly, Healthy People 2020 Objective CKD—2 is to "increase the proportion of persons with chronic kidney disease (CKD) who know they have impaired renal function." Screening and early detection provides the opportunity for interventions to foster awareness, adherence to medications, risk factor control, and improved outcomes. Additional data collection is required to precisely define the incremental benefits of early detection on kidney failure, cardiovascular events, hospitalization and mortality. Increasing the proportion of persons with CKD who know they are affected requires expanded public and professional education programs and screening initiatives targeted at populations who are at high risk for CKD. As a result of consistent congressional support, the National Center for Chronic Disease Prevention and Health Promotion at CDC has instituted a series of projects that could assist in attaining the Healthy People 2020 objective. However, this forward momentum will be stifled and CDC's investment in CKD to date jeopardized if line-item funding is not continued.

As noted in CDC's Preventing Chronic Disease: April 2006, Chronic Kidney Disease meets the criteria to be considered a public health issue: (1) the condition places a large burden on society; (2) the burden is distributed unfairly among the overall population; (3) evidence exists that preventive strategies that target economic, political, and environmental factors could reduce the burden; and (4) evidence shows such preventive strategies are not yet in place. Furthermore, CDC convened an expert panel in March 2007 to outline recommendations for a comprehensive public health strategy to prevent the development, progression, and complications of CKD in the United States.

The CDC Chronic Kidney Disease program has consisted of three projects to promote kidney health by identifying and controlling risk factors, raising awareness, and promoting early diagnosis and improved outcomes and quality of life for those living with CKD. These projects have included the following:

- (a) Demonstrating effective approaches for identifying individuals at high risk for chronic kidney disease through State-based screening (CKD Health Evaluation and Risk Information Sharing, or CHERISH).
- (b) Conducting an economic analysis by the Research Triangle Institute, under contract with the CDC, on the economic burden of CKD and the cost-effectiveness of CKD interventions.
- (c) Establishing a surveillance system for Chronic Kidney Disease. Development of a surveillance system by collecting, integrating, analyzing, and interpreting information on CKD using a systematic, comprehensive, and feasible approach will be instrumental in prevention and health promotion efforts for this chronic disease. The CDC CKD surveillance project has built a basic system from

¹Josef Coresh, et al. "Prevalence of Chronic Kidney Disease in the United States," *JAMA*, November 7, 2007.

²D.T. Gilbertson, et al., *Projecting the Number of Patients with End-Stage Renal Disease in the United States to the Year 2015*. *J Am Soc Nephrol* 16: 3736–3741, 2005.

³Mark J. Sarnak, et al. Kidney Disease as a Risk Factor for the Development of Cardiovascular Disease: A Statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. *Circulation* 2003; 108: 2154–69.

a number of data sources, produced a report and created a website program <http://www.cdc.gov/diabetes/projects/kidney/consisting> of information on preventing and controlling risk factors, the importance of early diagnosis, and strategies to improve outcomes. The website, publicly available for clinicians, health professionals, public health policy makers, and patients, also provides links to a number of publications and reports. The next steps include exploring State-based CKD surveillance data ideal for public health interventions through the State department of health.

We believe it is possible to distinguish between the CKD program and other categorical chronic disease initiatives at CDC, because the CKD program does not provide funds to State health departments. Instead, CDC has been making available seed money for feasibility studies in the areas of epidemiological research and health services investigation.

In summary, undetected Chronic Kidney Disease can lead to costly and debilitating irreversible kidney failure. However, cost-effective interventions are available if patients are identified in the early stages of CKD. With the continued expressed support of Congress, the National Kidney Foundation is confident a feasible detection, surveillance and treatment program can be established to slow, and possibly prevent, the progression of kidney disease.

Thank you for your consideration of our testimony.

PREPARED STATEMENT OF THE NATIONAL LEAGUE FOR NURSING

The National League for Nursing (NLN) is the premiere organization dedicated to promoting excellence in nursing education to build a strong and diverse nursing workforce to advance the Nation's health. With leaders in nursing education and nurse faculty across all types of nursing programs in the United States—doctorate, master's, baccalaureate, associate degree, diploma, and licensed practical—the NLN has more than 1,200 nursing school and health care agency members, 37,000 individual members, and 24 regional constituent leagues.

The NLN urges the subcommittee to fund the following Health Resources and Services Administration (HRSA) nursing programs:

- The Title VIII Nursing Workforce Development Programs at \$251.099 million in fiscal year 2014; and
- The Title III Nurse-Managed Health Clinics at \$20 million in fiscal year 2014.

Nursing Education is a Jobs Program

According to the U.S. Bureau of Labor Statistics (BLS), the registered nurse (RN) workforce will grow by 26 percent from 2010 to 2020, resulting in 711,900 new jobs. This growth in the RN workforce represents the largest projected numeric job increase from 2010 to 2020 for all occupations. The April 5, 2013, BLS Employment Situation Summary—March 2013 likewise reinforces the strength of the nursing workforce to the Nation's job growth. While the Nation's overall unemployment rate was little changed at 7.6 percent for March 2013, the employment in health care increased in March with the addition of 23,400 jobs at ambulatory health care services, hospitals, and nursing and residential care facilities, amounting to a full 26 percent of all jobs added in the month.

BLS notes that the health care sector is a critically important industrial complex in the Nation. It is at the center of the economic recovery with the number of jobs climbing steadily, in contrast to the erosion in so many other areas of the economy. Growing even when the recession began in December 2007, health care jobs are up nationwide by 10.5 percent. Compare that with all other jobs, which still are down, despite recent gains. If the health care economy had not expanded during the recession, the national unemployment rate would be 8.8 percent. Health care has been a stimulus program generating employment and income, and nursing is the predominant occupation in the health care industry, with more than 3.662 million active, licensed RNs in the United States in 2013.

The Nursing Workforce Development Programs provide training for entry-level and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. The Title VIII nursing education programs are fundamental to the infrastructure delivering quality, cost-effective health care. The NLN applauds the subcommittee's bipartisan efforts to recognize that a strong nursing workforce is essential to a health policy that provides high-value care for every dollar invested in capacity building for a 21st century nurse workforce.

The current Federal funding falls short of the health care inequities facing our Nation. Absent consistent support, slight boosts to Title VIII will not fulfill the expectation of generating quality health outcomes, nor will episodic increases in fund-

ing fill the gap generated by a 15-year nurse and nurse faculty shortage felt throughout the U.S. health system.

The Nurse Pipeline and Education Capacity

Although the recession resulted in some stability in the short-term for the nurse workforce, policy makers must not lose sight of the long-term growing demand for nurses in their districts and States. The NLN's findings from its Annual Survey of Schools of Nursing—Academic Year 2010–2011 cast a wide net on all types of nursing programs, from doctoral through diploma, to determine rates of application, enrollment, and graduation. Key findings include:

- Expansion of nursing education programs impeded by shortage of faculty.*—In fall 2011, the overall capacity of prelicensure nursing education continued to diminish well short of demand. Associate degree in nursing (ADN) programs rejected 51 percent of qualified applications, compared with 36 percent of baccalaureate of science in nursing (BSN) programs, and 25 percent in diploma programs. The Nation's practical nursing (PN) programs turned away 41 percent of qualified applications. With 32.2 percent of pre-licensure RN education programs citing lack of faculty as the main obstacle to expanding capacity, a strong correlation exists between the shortage of nurse faculty and the inability of nursing programs to keep pace with the demand for new RNs. Increasing the productivity of education programs is a high priority in most States, but faculty recruitment is a glaring problem. Without faculty to educate our future nurses, the shortage cannot be resolved.
- Demand for spots in post-licensure nursing education programs outstripped supply.*—The percentage of programs that turned away qualified applicants rose among every post-licensure program type between 2009 and 2011. Most strikingly, the percentage of master's of science in nursing (MSN) programs turning away qualified applicants jumped by 15 percent since 2009, i.e., from just one in three programs to almost half in 2011. Emerging from program acceptance rates (a.k.a. selectivity rates) was evidence of a scarcity of vacancies in post-licensure nursing programs, thus also indicating that competition was increasing: In 2011, just over one in four MSN programs and about one in six doctoral programs were highly selective. These trends threaten to perpetuate an unsafe cycle, constraining the number of graduates prepared to take on faculty roles in nursing schools.
- Yield rates continued to grow.*—Yield rates—a classic indicator of the competitiveness of college admissions—remain extraordinarily high among pre- and post-licensure nursing programs. A stunning 92 percent of all applicants accepted into ADN programs, and 92 percent of those accepted in PN programs, went on to enroll in 2011. Yield rates among the other program types were nearly as high, averaging 87 percent for RN-to-BSN programs; 88 percent for MSN programs; 89 percent for doctoral programs; 84 percent for RN diploma programs; and 80 percent for BSN programs.

Equally Pressing is Lack of Diversity

Our Nation is enriched by cultural diversity—37 percent of our population identify as racial and ethnic minorities. Yet ethnic, cultural, and gender diversity eludes the nursing student and nurse educator populations. A survey of nurse educators conducted by the NLN and the Carnegie Foundation's Preparation for the Professions Program found that only 7 percent of nurse educators were minorities compared with 16 percent of all U.S. faculty. The lack of faculty diversity limits nursing schools' ability to deliver culturally appropriate health professions education. In addition, the NLN survey for the 2010–2011 academic year reported that:

- African-American enrollment drops.*—The percentage of racial-ethnic minority students enrolled in pre-licensure RN programs has declined steadily over the past 2 years—ultimately dropping from a high of 29 percent in 2009 to 24 percent in 2011. The majority of that decline stems from a steep reduction in the percentage of African-American students enrolled in associate degree nursing programs, which dropped by almost 5 percent to 8.6 percent in just 2 years. BSN programs saw a small, but not significant drop, in African-American enrollment, down from 13 to 12 percent. Inversely, diploma programs saw a sharp rise in African-American enrollments, but because they represent just 4 percent of all basic RN programs, the impact is not great.
- Hispanic representation, while still lagging, inches upward.*—Hispanics remain dramatically underrepresented among nursing students. Representing a mere 6 percent of associate degree and baccalaureate nursing students, Hispanics were enrolled in basic nursing programs at less than half the rate at which they were enrolled in undergraduate programs overall. However, the percentage of His-

panics enrolled in post-licensure programs has nearly doubled over the past 2 years at every level. Hispanic enrollment rose from five to 12 percent in RN-to-BSN programs, from 5 to 10 percent in MSN programs, and 3 to 6 percent in doctoral programs. Hispanic enrollment in PN programs also jumped to over 11 percent in 2011.

—*Men's enrollment at historic high.*—While significantly less than the proportion in the U.S. population, at 15 percent, men enrolled in basic RN programs remained at the historic high reached at the start of the recession. Across all levels of nursing education, approximately 13 to 15 percent of nursing students were male in 2011, with the exception of doctoral programs where only 9 percent of students were male.

Besides representing an untapped talent pool to remedy the nursing shortage, ethnic, cultural, and gender-diverse minorities in nursing are essential to developing a health care system that understands and addresses the needs of our rapidly diversifying population. Workforce diversity is needed where research indicates that factors such as societal biases and stereotyping, communication barriers, limited cultural sensitivity and competence, and system and organizational determinants contribute to health care inequities.

Title VIII Federal Funding Reality

Today's undersupply of appropriately prepared nurses and nurse faculty does not bode well for our Nation. The Title VIII Nursing Workforce Development Programs are a comprehensive system of capacity-building strategies that provide students and schools of nursing with grants to strengthen education programs, including faculty recruitment and retention efforts, facility and equipment acquisition, clinical lab enhancements, and loans, scholarships, and services that enable students to overcome obstacles to completing their nursing education programs. A few examples of HRSA's Title VIII data below provide perspective on current Federal investments.

Nurse Education, Practice, Quality, and Retention Grants (NEPQR).—NEPQR funds projects addressing the critical nursing shortage via initiatives to expand the nursing pipeline, promote career mobility, provide continuing education, and support retention. Grantees funded to support the personal and home health aide purpose of the NEPQR program trained 1,366 students during fiscal year 2011; and grantees supporting the nursing assistant and home health aide NEPQR purpose supported 1,810 students.

Nursing Workforce Diversity (NWD).—NWD grants prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. Greater diversity among health professionals is associated with improved access to care for racial and ethnic minority patients, greater patient choice and satisfaction, and better patient-clinician communication. In addition, evidence suggests that minority health professionals are more likely to serve in areas with a high proportion of uninsured and underrepresented racial and ethnic groups. In fiscal year 2011, performance data showed that NWD grantees provided scholarships to 1,270 students, exceeding the performance target by 72 percent.

Nurse Faculty Loan Program (NFLP).—NFLP supports the establishment and operation of a loan fund at participating schools of nursing to assist nurses in completing their graduate education to become qualified nurse faculty. The NFLP seeks to increase the number and diversity of qualified nursing faculty. Faculty diversity is an essential ingredient in the efforts to diversify the nursing education pipeline and workforce overall. Ongoing NFLP support for faculty production is critical to building the pipeline needed to assure the full capacity of the Nation's future nursing workforce. Targeting a portion of those funds for minority faculty preparation is fundamental to achieving that goal. In fiscal year 2011, NFLP grantees provided loans to 2,246 students pursuing faculty preparation at the master's and doctoral levels, exceeding the program's performance target by 49 percent.

Nurse-Managed Health Clinics (NMHC)

NMHCs are defined as a nurse-practice arrangement, managed by advanced practice registered nurses, that provides primary care or wellness services to underserved or vulnerable populations. NMHCs are associated with a school, college, university, or department of nursing, federally qualified health center, or independent nonprofit health or social services agency.

NMHCs deliver comprehensive primary health care services, disease prevention, and health promotion in medically underserved areas for vulnerable and specialized populations (e.g., veterans and/or families of active military). Approximately 58 percent of NMHC patients either are uninsured, Medicaid recipients, or self-pay. The complexity of care for these patients presents significant financial barriers, heavily affecting the sustainability of these clinics. While providing access points in areas

where primary care providers are in short supply, expansion of NMHCs also increases the number of structured clinical teaching sites available to train nurses and other primary care providers. NMHCs continue to collaborate with federally Qualified Health Centers, Area Health Education Centers, and rural- and community-based clinics to provide training to some 5,000 nursing and other health professions students. Appropriating \$20 million in fiscal year 2014 to NMHCs would increase access to primary care for thousands of uninsured people in underserved urban communities.

The NLN can state with authority that the deepening health inequities, inflated costs, and poor quality of health care outcomes in this country will not be reversed until the concurrent shortages of nurses and qualified nurse educators are addressed. Your support will help ensure that nurses exist in the future who are prepared and qualified to take care of you, your family, and all those who will need our care. Without national efforts of some magnitude to match the health care reality facing our Nation today, a hardship in nurse education and its adverse effect in health care generally will be difficult to avoid.

The NLN urges the subcommittee to strengthen the Title VIII Nursing Workforce Development Programs by funding them at a level of \$251.099 million in fiscal year 2014. We also recommend that the Title III Nurse-Managed Health Clinics be funded at \$20 million in fiscal year 2014.

PREPARED STATEMENT OF THE NATIONAL MARFAN FOUNDATION (NMF)

NMF Fiscal Year 2014 LHHS Appropriations Recommendations

- Protect medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.
- Provide \$7.8 billion for CDC, an increase of \$1.7 billion over fiscal year 2012, including proportional increases for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to facilitate life saving awareness and education activities focused on early recognition and proper diagnosis of Marfan syndrome and related heritable connective tissue disorders.
- Provide \$32 billion for NIH, an increase of \$1.3 billion over fiscal year 2012, including proportional increases for the National Heart, Lung, and Blood Institute (NHLBI); National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS); National Eye Institute (NEI); National Center for Advancing Translational Sciences (NCATS); Office of Rare Diseases Research (ORDR); Office of the Director (OD); and other NIH Institutes and Centers to facilitate adequate growth in the Marfan syndrome and related heritable connective tissue disorders research portfolio.

Chairman Harkin, Ranking Member Moran, and distinguished members of the subcommittee, thank you for the opportunity to submit testimony on behalf of NMF. It is my honor to represent the estimated 200,000 Americans who are affected by Marfan syndrome or a related heritable connective tissue disorder.

About NMF

NMF is a non-profit voluntary health organization founded in 1981. NMF is dedicated to saving lives and improving the quality of life for individuals and families affected by the Marfan syndrome and related disorders. The Foundation has three major goals: 1) To provide accurate and timely information about the Marfan syndrome to affected individuals, family members, physicians, and other health professionals. 2) To provide a means for those with Marfan syndrome and their relatives to share in experiences, to support one another, and to improve their medical care. 3) To support and foster research.

About Heritable Connective Tissue Disorders

Marfan syndrome is a genetic disorder of the connective tissue that can affect many areas of the body, including the heart, eyes, skeleton, lungs and blood vessels. It is a progressive condition and can cause deterioration in each of these body systems. The most serious and life-threatening aspect of the syndrome is a weakening of the aorta. The aorta is the largest artery carrying oxygenated blood from the heart. Over time, many Marfan syndrome patients experience a dramatic weakening of the aorta which can cause the vessel to dissect and tear.

Aortic dissection is a leading killer in the United States, and 20 percent of the people it affects have a genetic predisposition, like Marfan syndrome, to developing the complication. Early surgical intervention can prevent a dissection and strength-

en the aorta and the aortic valves, especially when preventive surgery is performed before a dissection occurs.

Deficit Reduction and Sequestration

As you work with your colleagues in Congress on deficit reduction, budget, and appropriations issues please support the Marfan syndrome community by actively pursuing meaningful funding increases for critical medical research and healthcare programs. Our Nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH currently supports a meaningful research portfolio in Marfan syndrome coordinated through NIAMS and NHLBI. The research funded through this portfolio is conducted at academic health centers across the country, which has a direct impact on local economic activity. Further, while more work needs to be done, the commitment to NIH's Marfan syndrome and related disorders research portfolio over the years has greatly increased our scientific understanding of these conditions.

If Federal funding for Marfan syndrome research is substantially reduced, the current effort to capitalize on recent advancements and develop treatment options will face a serious setback. Ongoing research projects will stall and critical new research projects, particularly new activities coordinated by NEI, NCATS, and ORDR will not be initiated.

In addition, reducing support for Federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. The damage done now to the research training and career development pipeline could last for decades and undermine this country's entire biomedical research industry. It should also be noted that the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure.

The Marfan syndrome community is concerned that if healthcare programs endure significant funding cuts, patients will see few improvements in health and healthcare over the coming years.

Centers for Disease Control and Prevention

NMF joins the other voluntary health groups in requesting that you support CDC by providing the agency with an appropriation of \$7.8 billion in fiscal year 2014. Such a funding increase would allow CDC to undertake critical Marfan syndrome and related connective tissue disorders education and awareness activities, which would help prevent deadly thoracic aortic aneurysms and dissections.

In 2010, the American College of Cardiology and the American Heart Association issued landmark practice guidelines for the treatment of thoracic aortic aneurysms and dissections. NMF is promoting awareness of the new guidelines in collaboration with other organizations through a new Coalition known as "TAD"; the Thoracic Aortic Disease Coalition. The TAD Coalition is presently comprised of 10 organizations that are coordinating efforts to help promote the Guidelines to healthcare professionals and to raise public awareness of various aortic diseases and the associated risk factors.

The CDC would be an invaluable partner in the ongoing campaign to save lives and improve health outcomes by promoting the new Guidelines to healthcare providers and raising public awareness of risk factors. In this regard, we ask the subcommittee encourage CDC to identify appropriate staff at the NCCDPHP and NCBDDD to participate in TAD Coalition activities. It is our hope that involving CDC in the activities of the TAD Coalition will lead to a lasting partnership and collaboration on critical outreach campaigns.

National Institutes of Health

NMF joins the broader public health community in requesting that you support NIH by providing the agency with an appropriation of \$32 billion in fiscal year 2014. This modest 4 percent funding increase would ensure that biomedical research inflation does not result in a loss of purchasing power at NIH, critical new initiatives like the Cures Acceleration Network (CAN) are adequately supported, and that the Marfan syndrome research portfolio can continue to make progress.

NHLBI.—Critical investment in research activities by NHLBI has greatly improved our scientific understanding of Marfan syndrome and related heritable connective tissue disorders. These breakthroughs have lead to subsequent improvements in healthcare and treatment options.

NIAMS.—The Marfan syndrome and related connective tissue disorders research portfolio at NIAMS has been crucial to the effort to improve the lives of individuals living with these conditions. The NIAMS research portfolio lead the way in identi-

finding many genetic factors for these conditions and still supports major advances in the pathophysiology of the disease.

NEI.—Marfan syndrome is associated with eye problems and vision loss. However, we do not currently have a firm understanding of the link and NEI is only just beginning to initiate research projects in this area.

NCATS.—The Office of Rare Diseases Research has long supported important Marfan syndrome research. Further, emerging programs at NCATS intended to ensure that scientific breakthroughs are translated to meaningful treatment options hold tremendous promise for the Marfan syndrome and heritable connective tissue disorders community.

Thank you for your time and your consideration of these requests. Please contact me if you have any questions or if you would like any additional information.

PREPARED STATEMENT OF THE NATIONAL MINORITY CONSORTIA

The National Minority Consortia (NMC) submits this statement on the fiscal year 2016 advance appropriations for the Corporation for Public Broadcasting (CPB). We represent a coalition of five national organizations, who, with modest support from CPB, bring authentic stories of diversity to the Nation. We bring unique voices and perspectives from America's diverse communities into all aspects of public broadcasting and other media, including content transmitted digitally over the Internet. Our requests are two: 1) That Congress direct CPB to meaningfully increase its commitment to diverse programming and serving underserved communities; and 2) that at least \$445 million be provided in advance fiscal year 2016 funding for CPB. We ask the Committee to:

- (1) *Direct CPB to increase its efforts for diverse programming with a commitment for minority programming and for organizations and stations located within underserved communities.*—We urge Congress in bill and/or report language to recognize that CPB, while it has enabled diversity in public broadcasting, still has very far to go. We suggest language such as:

The Committee recognizes the importance of the partnership CPB has with the National Minority Consortia, which helps develop, acquire, and distribute Public Television programming to serve the needs of African American, Alaska Native, Asian American, Latino, Native American, and Pacific Islander peoples. These stories of diversity transcend statistics and bring universal American stories to all Americans. As communities across the country welcome increased numbers of citizens of diverse ethnic backgrounds, local Public Television stations must strive to meet these viewers' needs. The Committee encourages CPB to support and expand this critical partnership, including instituting funding guidelines that encourage and reward public media that represent and reach a diverse American public.

CPB has a big responsibility with regard to diversity, yet the five NMC organizations combined receive only \$7.5 million in discretionary funds from CPB, an amount less than 2 percent of the CPB budget. And this amount has been decreased by 10 percent due to the sequestration.

- (2) Provide fiscal year 2016 advance appropriation for CPB of \$445 million, in order to develop content that reaches across traditional media boundaries, such as those separating television and radio.

While public broadcasting continues to uphold strong ethics of responsible journalism and thoughtful examination of American history, life and culture, it has not kept pace with our rapidly changing demographics. Members of minority groups continue to be underrepresented on programming and oversight levels within and in content production. This is unacceptable in America today, where minorities comprise over 36 percent of the population. This becomes more urgent now that racial and ethnic minorities make up more than half of all children born in the United States today.

Public broadcasting has the potential to be particularly important for our growing minority and ethnic communities, especially as we transition to a broadband-enabled, 21st century workforce that relies on the skills and talent of all of our citizens. While there is a niche in the commercial broadcast and cable world for quality programming about our communities, it is in the public broadcasting sphere where minority communities and producers should have more access and capacity to produce diverse high-quality programming for national audiences. We therefore, urge Congress to insert strong language in this

act to ensure that this is the case and that these opportunities are made available to minorities and other underserved communities.

About the National Minority Consortia.—With primary funding from the CPB, the NMC serves as an important component of American Public Television content—on air and over the Internet. By developing and funding diverse content, training and mentoring the next generation of minority producers and program managers, as well as brokering relationships between content makers and distributors, we are in a position to ensure the future strength and relevance of Public Television and radio television content from and to our communities.

Each Consortia organization is engaged in cultivating ongoing relationships with the independent producer community by providing technical assistance and program funding, support and distribution. Often the funding we provide is the initial seed money for a project, that is matched by other public and private sources, providing true economic development. We also provide numerous hours of programming to individual Public Television and radio stations—programming that is beyond the reach of most local stations. To have a real impact, we need funding that recognizes and values the full extent of minority participation in public life. Below is information regarding each of the five NMC organizations.

Center for Asian American Media (CAAM).—CAAM's mission is to present stories that convey the richness and diversity of Asian American experiences to the broadest audience possible. We do this by funding, producing, distributing and exhibiting works in film, television and digital media. Over CAAM's 33-year history they have provided funding to more than 200 projects, many of which have gone on to win Academy, Emmy and Sundance awards, examples of which are *Days of Waiting*; *Of Civil Rights and Wrongs: The Fred Korematsu Story*; *Maya Lin: A Strong Clear Vision*; *The Betrayal (Nerakhoon)*, *Visas and Virtues*; and *Up the Yangtze*. CAAM presents the annual CAAMFest (formerly known as the San Francisco International Asian American Film Festival) and distributes Asian American media to schools, libraries and colleges. CAAM's newest department, Digital Media, is becoming a respected leader in bringing innovative content and audience engagement to public media. CAAM also presented the documentary on ukulele sensation Jake Shimabukuro: *Life on Four Strings* on national PBS with our partner Pacific Islanders in Communications.

Latino Public Broadcasting (LPB).—LPB supports the development, production and distribution of public media content that is representative of the diverse Latino community in this country. LPB has provided over 170 hours of engaging Latino programs to the PBS and beyond the broadcast, into communities, colleges and universities through screenings and forums. Emmy nominated *The Longoria Affair* reached over 20,000 participants through forums in 10 States and has become part of the curriculum in 100 colleges. VOCES on PBS is the only series on Public Television that explores the rich diversity of the Latino cultural experience. From its content, LPB creates standards-based curriculum for the PBS Learning Media, a free service into the schools with 850,000 registered teachers. These resources on Latino history and culture enrich the learning experience of young children, particularly Latinos who have one of the Nation's highest drop-out rates. In the Fall of 2013, LPB and WETA will present *Latino Americans*, a 6-part series on the varied history of Latinos who have helped shape the Nation over the last 500-plus years and have become, with more than 50 million people, the largest minority group in the Nation.

National Black Programming Consortium/Black Public Media works to increase capacity in diverse communities to create, distribute and use public media. Throughout its history, its mission has been two-fold: building capacity in new generations of creators of social issue media and broadening the pool of stakeholders in public media institutions. Over the past 6 years, in addition to supporting producers who create programming for Public Television and other platforms, NBPC/Black Public Media has convened and mentored over 500 digital media professionals and created the Public Media Corps (PMC) to address an urgent need in our communities at the grassroots level. In 2013, NBPC/Black Public Media presented the fifth season of the critically-acclaimed series *AfroPop: the Ultimate Cultural Exchange*, which features independent perspectives from the African diaspora, and released the second season of our hit web exclusive series *Black Folk Don't*, a documentary satire that challenges the common stereotypes. In late March, NBPC/Black Public Media premieres *180 Days: A Year Inside an American High School*, a PBS Special about the challenges of school reform. "180 Days" is connected to CPB's American Graduate initiative to combat the drop out crisis in American public schools.

Pacific Islanders in Communications (PIC).—PIC's mission is to support, advance, and develop Pacific Island media content and talent that results in a deeper understanding of Pacific Island history, culture, and contemporary challenges. In keeping with the mission, PIC helps Pacific Islander stories reach national audiences through funding support for productions, training and education, broadcast services, and community engagement. Last year alone, PIC provided seven hours of content. In the past 10 years, PIC has produced approximately 65 hours of programming for national broadcast, trained over 350 Pacific Islander filmmakers, and have had over 100 community screenings worldwide with more than 54,000 people in attendance. This year, PIC partnered with National Geographic to broadcast *The Mystery of Easter Island* on NOVA, which refutes earlier claims that the Rapanui people were responsible for their own cultural destruction and *Fixing Juvie Justice*, which explores the Polynesian model of restorative justice used in the U.S. juvenile criminal system. PIC's series *Pacific Heartbeat*, reached over 24 million households last year. Its second season begins in May 2013.

Vision Maker Media (VMM) (formerly Native American Public Telecommunications) shares Native stories with the world that represent the cultures, experiences, and values of American Indians and Alaska Natives. Founded in 1977, Vision Maker Media presented seven Native American documentaries to PBS stations nationwide this year—*Grab*; *Racing the Rez*; *Standing Bear's Footsteps*; *POV: Up Heartbreak Hill*; *America Reframed: My Louisiana Love*; *Sousa on the Rez*; and *Need to Know: America by Numbers*. We also offered producers and educators numerous workshops across the Nation. Vision Maker Media programming reaches beyond the broadcast with interactive web content, standards-based curriculum, and Viewer Discussion Guides. Vision Maker Media continues to work with local stations to bring new voices into the public broadcasting. We developed community engagement strategies to support CPB's American Graduate initiative.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and we thank Congress for support of our work on behalf of our communities.

PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Chairman and Members of the Committee, thank you for this opportunity to provide testimony regarding funding of critically important Federal programs that impact those affected by multiple sclerosis. Multiple sclerosis (MS) is an unpredictable, often disabling disease of the central nervous system that interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease.

The National MS Society sees itself as a partner to the Government in many critical areas. As we advocate for NIH research, we do so as an organization that funds over \$40 million annually in MS research through funds generated through the Society's fundraising efforts. And as we advocate for Lifespan Respite funding, we do so as an organization that works to provide some level of respite relief for caregivers. So while we're here to advocate for Federal funding, we do it as an organization that commits tens of millions of dollars each year to similar or complementary efforts as those being funded by the Federal Government. Through these efforts, our goal is to see a day when MS has been stopped, lost functions have been restored, and a cure is at hand.

We would like to take this time to highlight for the subcommittee the importance of five key agencies/programs that have a direct impact on people living with MS as it discusses the fiscal year 2014 budget.

NATIONAL INSTITUTES OF HEALTH

We urge Congress to continue its investment in innovative medical research that can help prevent, treat, and cure diseases such as MS by appropriating at least \$32 billion in fiscal year 2014.

The NIH is the country's premier institution for medical research and the single largest source of biomedical research funding in the world. The NIH conducts and

sponsors a majority of the MS related research carried out in the United States. Approximately \$115 million of fiscal year 2012 and Recovery Act appropriations (the last available data) were directed to MS-related research. An invaluable partner, the NIH has helped make significant progress in understanding MS. NIH scientists were among the first to report the value of MRI in detecting early signs of MS, before symptoms even develop. Advancements in MRI technology allow doctors to monitor the progression of the disease and the impact of treatment.

Research during the past decade has enhanced knowledge about how the immune system works, and major gains have been made in recognizing and defining the role of this system in the development of MS lesions. These NIH discoveries are helping find the cause, alter the immune response, and develop new MS therapies that are now available to modify the disease course, treat exacerbations, and manage symptoms. Twenty years ago there were no MS therapies or medications. Now there are nine, with the two new oral medications now available and other new treatments in the pipeline. The NIH provided the basic research necessary so that these therapies could be developed. Had there been no Federal investment in research, it's doubtful people living with MS would have any therapies available. The NIH also directly supports jobs in all 50 States and 17 of the 30 fastest growing occupations in the U.S. are related to medical research or health care. More than 83 percent of the NIH's funding is awarded through almost 50,000 competitive grants to more than 325,000 researchers at over 3,000 universities, medical schools, and other research institutions in every State.

CENTERS FOR MEDICARE & MEDICAID SERVICES

Medicare

Medicare is an extremely important program for many living with MS. It is estimated that over 20 percent of the MS population relies on Medicare as its primary insurer. The majority of these individuals are under the age of 65 and receive the Medicare benefit as a result of their disability. While sequestration excluded any cuts that would directly impact Medicare beneficiaries, the Society would like to remind Congress of the importance of having appropriate reimbursement levels for physicians to ensure participation in Medicare, promoting policies to allow access to diagnostics and durable medical equipment and discouraging overly burdensome cost-sharing for prescription drugs.

Medicaid

The National MS Society urges Congress to maintain funding for Medicaid and reject proposals to cap or block grant the program.

Medicaid provides comprehensive health coverage to over eight million persons living with disabilities, plus six million persons with disabilities who rely on Medicaid to fill Medicare's gaps. The latest statistics (which are pre-recession) show that about 5–10 percent of people with MS have Medicaid coverage. While that is a small figure, for these individuals, Medicaid is truly a safety net. The most recently available data (2007) reveals that the average annual direct and indirect (e.g. lost wages) cost for someone with MS in the U.S. is approximately \$69,000. After years of paying to manage their disease, some people with MS have spent the vast majority of their earnings and savings, making their financial situation so dire that they meet Medicaid's low income eligibility requirements.

Some policymakers have proposed capping or block granting Medicaid or more recently, placing a "per capita cap" whereby the Federal Government would limit each State to a fixed dollar amount per beneficiary. Any of these proposals would merely shift costs to States, forcing States to shoulder a seemingly insurmountable financial burden or cut services on which our most vulnerable rely. It could result in more individuals becoming uninsured, compounding the current problems of lack of coverage, overflowing emergency rooms, limited access to long-term services, and increased healthcare costs in an overburdened system. Also, by capping funds that support home- and community-based care, the proposals could lead to an increased reliance on costlier institutional care that contradicts the principles laid forth in the 1999 U.S. Supreme Court decision *Olmstead* and integrating and keeping people with disabilities in their communities.

While the economic situation demands leadership and thoughtful action, the National MS Society urges Congress to remember people with MS and all disabilities, their complex health needs, and the important strides Medicaid has made for persons living with disabilities particularly in the area of community-based care, and not modify the program to their detriment.

SOCIAL SECURITY ADMINISTRATION

The National MS Society urges Congress to provide \$12.3 billion for the Social Security Administration's (SSA) administrative budget in fiscal year 2014.

Because of the unpredictable nature and sometimes serious impairment caused by the disease, SSA recognizes MS as a chronic illness or "impairment" that can cause disability severe enough to prevent an individual from working. During such periods, people living with MS are entitled to and rely on Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits to survive. People living with MS, along with millions of others with disabilities, depend on SSA to promptly and fairly adjudicate their applications for disability benefits and to handle many other actions critical to their well-being including: timely payment of their monthly benefits; accurate withholding of Medicare Parts B and D premiums; and timely determinations on post-entitlement issues, e.g., overpayments, income issues, prompt recording of earnings.

Providing \$12.3 billion would allow SSA to cover inflationary increases, continue efforts to reduce hearings and disability backlogs, increase deficit-reducing program integrity work, and replace some critical staffing losses in SSA's components. It would also help to minimize the closure of additional field offices. In the last 2 years, SSA closed a number of field offices due to limited resources. In many cases, applicants for benefits or those approaching retirement age who have questions about their eligibility or benefits have been forced to travel greater distances to visit a Social Security field office.

The disability backlog is also an area of serious concern. Since fiscal year 2008, the number of claims pending for a disability medical decision rose from 565,286 to 707,700—an increase of 142,414, or 25.2 percent. Despite the fact that claims have exceeded three million for four successive years, the current staffing level for DDSs is 14,262, which is 1,107 (7.2 percent) below the level at the end of fiscal year 2011, and 1,831 (11.3 percent) below the level at the end of fiscal year 2010. SSA was making progress in addressing the enormous backlog of hearings cases, but resource issues have magnified the challenges. In June 2010, the number of pending hearings was down to 694,417 but by May 2012, it reached an all-time high of 823,828. Even with the dramatic increase in the volume of new hearing requests filed over the last few years, processing time has been reduced from 491 days in fiscal year 2009 to 353 days in September 2012. If SSA does not receive adequate funding, this progress will regress and the disability hearings backlog will continue to mount, denying people with MS and other disabilities timely determinations and dispensing of benefits.

LIFESPAN RESPITE CARE PROGRAM

Up to one quarter of individuals living with MS require long-term care services at some point during the course of the disease. Often, a family member steps into the role of primary caregiver to be closer to the individual with MS and to be involved in care decisions. According to a 2011 AARP report, 61.6 million family caregivers provided care at some point during 2009 and the value of their uncompensated services was approximately \$450 billion per year—more than total Medicaid spending and almost as high as Medicare spending. Family caregivers allow the person living with MS to remain home for as long as possible and avoid premature admission to costlier institutional facilities.

Family caregiving, while essential, can be draining and stressful, with caregivers often reporting difficulty managing emotional and physical stress, finding time for themselves, and balancing work and family responsibilities. A 2012 National Alliance for Caregiving (NAC) survey of individuals providing care to people living with MS shows that on average, caregivers spend 24 hours a week providing care. Sixty 4 percent of caregivers were emotionally drained, 32 percent suffered from depression and 22 percent have lost a job due to caregiving responsibilities. In the broader caregiving community, it has been estimated that American businesses lose \$17.1 to \$33.36 billion each year due to lost productivity costs related to caregiving responsibilities.

The Lifespan Respite Care Program, signed into law in 2006 by President Bush, provides competitive grants to States to establish or enhance statewide lifespan respite programs that better coordinate and increase access to quality respite care. Respite offers professional short-term help to give caregivers a break from the stress of providing care and has been shown to provide family caregivers with the relief necessary to maintain their own health and bolster family stability. With Lifespan Respite funding, State grantees have developed or enhanced statewide databases of respite care services, developed person-centered respite service options such as vouchers, and trained more volunteer and paid respite providers.

Perhaps the most critical aspect of the program for people living with MS is that Lifespan Respite serves families regardless of special need or age—literally across the lifespan. Much existing respite care has age eligibility requirements and since MS is typically diagnosed between the ages of 20 and 50, Lifespan Respite programs are often the only open door to needed respite services. The National MS Society asks that Congress preserve funding for the Lifespan Respite program in fiscal year 2014 so that people with MS can remain at home, and family caregivers can remain productive members of the community and workforce and American businesses no longer suffer the monstrous financial impact caregiver strain currently has on them. For the past few fiscal cycles, Lifespan Respite has received approximately \$2.5 million.

CONCLUSION

The National MS Society thanks the Committee for the opportunity to provide written testimony and our recommendations for fiscal year 2014 appropriations. The agencies and programs we have discussed are of vital importance to people living with MS and we look forward to continuing to working with the Committee to help move us closer to a world free of MS. Please don't hesitate to contact me with any questions.

PREPARED STATEMENT OF THE NATIONAL NURSING CENTERS CONSORTIUM

My name is Tine Hansen-Turton, and I am the CEO of the National Nursing Centers Consortium (NNCC). On behalf of the NNCC, I would like to thank the members of this subcommittee for the opportunity to submit testimony regarding the importance of appropriating funds to support nurse-managed health clinics. Specifically, NNCC and its members request an appropriation of \$20 million to support grants to nurse-managed health clinics through the Nurse Managed Health Clinic Grant Program established under Title III of the Public Health Service Act.

NNCC is a 501(c)(3) member association of nonprofit, nurse-managed health clinics, sometimes called nurse-managed health centers or NMHCs. The Affordable Care Act (ACA) defines the term 'nurse-managed health clinic' as a nurse practice arrangement, managed by advanced practice nurses, that provides primary care or wellness services to underserved or vulnerable populations and that is associated with a school, college, university or department of nursing, federally qualified health center (FQHC), or independent nonprofit health or social services agency.¹ Currently there are approximately 250 NMHCs in operation throughout the United States. The Nurse Managed Health Clinic Grant Program was created to provide NMHCs with a stable source of Federal funding that would place them on footing similar to other safety-net providers. Although authorized, to date the Grant Program has received no appropriations.

The Value of NMHCs and the Need for NMHC Grant Funding

NMHCs Expand Primary Care Workforce Capacity.—The Nation is facing a primary care crisis that is about to get worse. According to the Association of American Medical Colleges (AAMC), by 2025 there will be a dearth of 130,600 physicians, which includes a shortage of 65,800 primary care physicians.² AAMC data also shows that American medical schools are not graduating enough doctors to meet this need. In fact, the number of family practice residencies across the Nation has been in decline for the past 12 years, and medical schools have not filled available family practice residencies in the past 3 years.³ The Congressional Budget Office estimates the Medicaid expansion called for by the ACA will lead to 11 million new enrollees.⁴ As these new enrollees establish primary care homes, the burden on the primary care workforce is likely to increase dramatically.

Data from Massachusetts shows just how bad the problem could get. A study conducted 2 years after that State expanded its public coverage through health care reform legislation found that only 52 percent of internists in Massachusetts were accepting new patients and one out of every three family physicians was no longer

¹ Section 5208 of the Affordable Care Act.

² American Association of Medical Colleges (AAMC) Center for Workforce Studies.

³ American Association of Medical Colleges (AAMC) Center for Workforce Studies.

⁴ CBO. Estimates for the Insurance Coverage Provisions of the Affordable Care Act Updated for the Recent Supreme Court Decision. (July 2012). p 13. Retrieved on February 28, 2013 from <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf>.

accepting new patients.⁵ Another study completed 1 year later, found that the average wait time to see a physician in Boston was 49.6 days, the longest in the Nation.⁶

NMHCs are primarily managed by nurse-practitioners which make up the fastest growing segment of primary care providers in the country.⁷ Currently there are 155,000 NPs in the country and the numbers are growing quickly.⁸ Because of their growing numbers, policy makers across the country are calling for nurse practitioners and NMHCs to assume a greater role in primary care. For example, in its report, "The Future of Nursing: Leading Change, Advancing Health," the Institute of Medicine (IOM) states, "advanced practice registered nurses should be called upon to fulfill and expand their potential as primary care providers across practice settings based on their education and competency."⁹ When discussing the role of NMHCs, the IOM report says, "Nurse-managed health clinics offer opportunities to expand access; provide quality, evidence-based care; and improve outcomes for individuals who may not otherwise receive needed care."¹⁰

Along with the IOM, the National Governor's Association (NGA) and the National Institute for Health Care Reform (NIHCR) have released reports identifying the greater use of nurse practitioners as a possible means of alleviating the pressure on the primary care workforce. The NGA report titled, "The Role of Nurse Practitioners in Meeting Increasing Demand for Primary Care," was published in December of 2012. Published in February of 2013, the NIHCR research brief was titled, "Primary Care Workforce Shortages: Nurse Practitioner Scope-of-Practice Laws and Payment Policies."

As safety-net providers, NMHCs offer medically underserved patients high quality primary care that is available regardless of the patient's ability to pay. Because they already serve a high percentage of Medicaid patients, the clinics are perfectly positioned to fill the gaps in care that will result from the ACA's proposed Medicaid expansion. However, because they often cannot meet the requirements for federally-qualified health center (FQHC) funding, many NMHCs are struggling financially. The NMHC Grant Program was created to place NMHCs on a similar footing with other safety-net providers by giving NMHCs an alternative source of Federal funding.

In order to lessen the primary care crisis, and ensure the underserved can take full advantage of the care NMHCs offer, NNCC requests that the subcommittee appropriate funding to the NMHC grant program. Evidence suggests that doing this will not only expand access but also lower the cost of care. In addition to having lower labor costs, research shows that NMHCs cut costs by reducing unnecessary emergency room visits and hospitalizations.¹¹

NMHCs Help Educate the Health Professionals of Tomorrow.—The main reason NMHCs have difficulty qualifying for FQHC funding is because many are affiliated with academic schools of nursing. Because academically-affiliated NMHCs operate under the jurisdiction of a university, most cannot meet FQHC governance requirements without breaking their academic connection and giving up their clinical programs. Ironically, however, these academic affiliations mean that the NMHC model emphasizes the workforce development that is so needed with the Medicaid expansion under the Affordable Care Act. NMHCs naturally serve as community-based clinical training sites for a diverse group of health profession students including registered nurses and advance practice nurses (mostly nurse practitioners), medical, pharmacy, dental, social work, public health, and other students.

In October of 2010, HRSA released \$14.8 million in Prevention and Public Health Fund dollars to fund ten NMHC grants. In addition to serving over 27,000 patients and recording more than 72,000 encounters, the NMHC grantees have provided interdisciplinary clinical training to over 800 health profession students annually.¹² In 2012, the NNCC conducted a survey of its members to measure their contribution to health professions education. Twenty-eight NMHCs in a mix of urban, rural, and suburban communities reported providing educational opportunities for nearly 1,500

⁵Massachusetts Medical Society, "2008 Physician Workforce Study: Executive Summary," available at: www.massmed.org/workforce.

⁶USA Today, "Wait Times to See Doctors are Getting Longer," available at: http://usatoday30.usatoday.com/news/health/2009-06-03-waittimes_N.htm.

⁷Statement of A. Bruce Steinwald, Health Care Director, U.S. Government Accountability Office, Testimony Before the Committee on Health, Labor, Pensions, U.S. Senate, February 12, 2008.

⁸

⁹IOM, "the Future of Nursing: Leading Change, Advancing Health," page 1–2.

¹⁰IOM, "the Future of Nursing: Leading Change, Advancing Health," page c–4.

¹¹Coddington, J. A. & Sands, L. P. Cost of health care and quality outcomes of patients at nurse-managed clinics. *Nurs Econ*, 26(2), 75–83. (2008).

¹²Special survey of NMHCs funded under the ACA. Conducted by NNCC in 2011.

students.¹³ The average number of students educated by the NMHC grant funded clinics was 80, while the clinics participating in the 2012 survey reported educating an average of 55 students. This data tells us two important things: 1) the contribution of NMHCs to workforce development is undeniable; 2) the ability of NMHCs to offer educational opportunities is greatly enhanced with increased funding.

In post-clinical focus groups students have reported being “overwhelmingly satisfied” with their experience in NMHC clinical rotations. Other feedback suggested that NMHCs are filling a gap in nursing education by providing community-based experience not found in other clinical rotations.¹⁴ The IOM report on the future of nursing also specifically praised NMHC clinical programs for their emphasis on interprofessional education which is an important factor in future job satisfaction, and building a more flexible workforce.

Despite the benefits of NMHC clinical programs, NMHC leaders are often forced to abandon this important piece of the NMHC model in order to qualify for FQHC funding. By providing an alternative source of funding for NMHCs, the Nurse-Managed Health Clinic grant program helps to preserve the contribution of NMHCs to workforce development. Given the country’s growing need for nurses, NNCC respectfully requests that the subcommittee members appropriate funding to support clinical programs and place NMHCs on a similar footing with other safety-net providers through the NMHC grant program.

Request.—The 10 NMHC grants distributed in 2010 will expire this year if Congress does not move to appropriate funding to the program. For all the reasons mentioned above, NNCC respectfully requests an appropriation of \$20 million in fiscal year 2014 for the Nurse-Managed Health Clinic Grant Program, as authorized under Title III of the Public Health Service Act.

PREPARED STATEMENT OF THE NATIONAL PRIMATE RESEARCH CENTERS

The Directors of the eight National Primate Research Centers (NPRCs) respectfully submit this written testimony for the record to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The NPRCs appreciate the commitment that the Members of this subcommittee have made to biomedical research through your support for the National Institutes of Health (NIH) and recommends providing at least \$32 billion for NIH in fiscal year 2014. We believe this amount is the minimum level of funding needed to accommodate the rising costs of medical research and to help mitigate the effects of sequestration. The NPRCs also encourage the subcommittee to work to stop the sequestration cuts to research funding that squander invaluable scientific opportunities, threaten medical progress and continued improvements in our Nation’s health, and jeopardize our economic vitality.

The NPRCs respectfully request that the subcommittee provide strong support for the NIH Office of Research Infrastructure Programs (ORIP), housed within the NIH Office of the Director, which is the administrative home of the NPRCs. This support would help to ensure that the NPRCs and other animal research resource programs continue to serve effectively in their role as vital national resources.

The mission of the National Primate Research Centers is to use scientific discovery and nonhuman primate models to accelerate progress in understanding human diseases, leading to interventions, treatments, cures, and ultimately to overall better health of the Nation and the world. The NPRCs collaborate as a transformative and innovative network to develop and support the best science and act as a resource to the biomedical research community as efficiently as possible. There is an exceptional return on investment in the NPRC program; ten dollars is leveraged for every one dollar of research support for the NPRCs. It is important to sustain funding for the NPRC program and the NIH as a whole and to continue to grow and develop the innovative plan for the future of NIH.

The NPRCs are particularly concerned with the reduction of Federal funds to support research, including the 5 percent cut in NIH funding under sequestration. The cuts harm our Nation’s ability to advance scientific discoveries that improve human health, bolster the economy, and help keep our Nation globally competitive. Furthermore, the impact of sequestration has been compounded by ongoing funding constraints caused by 10 years of flat NIH budgets, which have resulted in a loss of purchasing power and affected the ability of NIH-funded scientists to pursue promising new avenues of research.

¹³ 2012 NNCC member survey.

¹⁴ Feedback from student focus groups conducted by the Institute for Nursing Centers in 2009.

At the same time that scientists are facing these funding challenges, they are poised like never before to capitalize on tremendous scientific opportunities and make paradigm-shifting discoveries to address our Nation's most pressing public health needs. Budget uncertainty is disruptive to training, careers, long-range projects, and ultimately, to research progress. To ensure the successful and efficient advancement of science, the research engine needs predictable, sustained funding that maximizes the Nation's return on investment.

Not only is NIH research essential to advancing health, it also plays a key economic role in communities nationwide. Approximately 85 percent of NIH funding is spent in communities across the Nation, creating jobs at more than 2,500 research institutes, universities, teaching hospitals, and other institutions. NIH research also supports long-term competitiveness for American workers, forming one of the key foundations for U.S. industries like biotechnology, medical device and pharmaceutical development, and more.

NPRCs' Contributions to NIH Priorities

The NPRCs' activities are closely aligned with NIH priorities. In fact, NPRC investigators conduct much of the Nation's basic and translational nonhuman primate research, facilitate additional vital nonhuman primate research that is conducted by hundreds of investigators from around the country, provide critical scientific expertise, train the next generation of scientists, and advance cutting-edge technologies.

As a part of the NIH Office of the Director, the NPRCs see a great opportunity to work with all NIH institutes and centers to further integrate the consortium as a trans-NIH resource on topics such as colony management, training, genetics and genome banking. Also, as the National Center for Advancing Translational Sciences (NCATS) identifies new approaches to translating basic discoveries into treatments and therapeutics, the NPRC consortium will work with the new center to bring to the fore the central role of nonhuman primate research in developing, and ensuring the effectiveness of, new medical products and interventions. Finally, we continue to engage as a resource for the Clinical and Translational Science Award (CTSA) network to help clinical researchers increase their knowledge of and access to nonhuman primates as animal models.

Outlined below are a few of the overarching goals and priorities for the NPRCs, including specifics of how the NPRCs are striving to achieve these through programs and activities across the centers.

Advance Translational Research Using Animal Models.—Nonhuman primate models bridge the divide between basic biomedical research and implementation in a clinical setting. Currently, seven of the eight NPRCs are affiliated and collaborate with an NIH CTSA program through their host institution. Specifically, the nonhuman primate models at the NPRCs often provide the critical translational link between research with small laboratory animals and studies involving humans. As the closest genetic model to humans, nonhuman primates serve in the process of developing new drugs, treatments, and vaccines to ensure safe and effective use for the Nation's public.

It is neither cost effective nor feasible to reproduce these specialized facilities and expertise at every research institution, so the NPRCs are a valuable resource to the research community. Major areas of research benefiting from the resources of the NPRCs include AIDS, avian flu, Alzheimer's disease, Parkinson's disease, autism, cardiovascular disease, diabetes, obesity, asthma, and endometriosis. To facilitate these and other studies, the NPRC have developed a resource of over 26,000 nonhuman primates, 70 percent of which are rhesus monkeys, the most widely used nonhuman primate for HIV research and a wide range of translational studies.

Strengthen the Research Workforce.—The success of the Federal Government's efforts in enhancing public health is contingent upon the quality of research resources that enable scientific research ranging from the most basic and fundamental to the most highly applied. Biomedical researchers have relied on one such resource—the NPRCs—for nearly 50 years for research models and expertise with nonhuman primates. The NPRCs are highly-specialized facilities that foster the development of nonhuman primate animal models and provide expertise in all aspects of nonhuman primate biology. NPRC facilities and resources are currently used by over 2,000 NIH funded investigators around the country.

The NPRCs are also supportive of students interested in the biomedical research at an early age. For example, the Yerkes NPRC supports a program that connects with local high schools and colleges in Atlanta, Georgia, and provides high school science students and teachers with summer-long internships to participate in research projects taking place at their center. Other NPRCs have similar programs that help develop a pipeline of aspiring science students and teachers.

The Need for Facilities Support

The NPRC program is a vital resource for enhancing public health and spurring innovative discovery. In an effort to address many of the concerns within the scientific community regarding the need for funding for infrastructure improvements, the NPRCs support the continuation of a robust construction and instrumentation grant program at NIH. Animal facilities, especially primate facilities, are expensive to maintain and are subject to abundant “wear and tear.” The NPRCs are dependent on strong support for the P51 base grant program which is essential for the operational costs, and the C06 and G20 programs which support construction and renovation of animal facilities. Without proper infrastructure, the ability for animal research facilities, including the NPRCs, to continue to meet the high demand of the biomedical research community will be unsustainable.

Thank you for the opportunity to submit this written testimony and for your attention to the critical need for primate research and the continuation of infrastructure support. We thank you for your support of NIH and urge you to provide at least \$32 billion for the agency in the fiscal year 2014 appropriations bill.

PREPARED STATEMENT OF THE NATIONAL PSORIASIS FOUNDATION

INTRODUCTION AND OVERVIEW

The National Psoriasis Foundation (the Foundation) appreciates the opportunity to submit written public witness testimony in support of \$1.2 million in fiscal year 2014 Federal funding for the implementation of the psoriasis and psoriatic arthritis public health agenda at the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). The Foundation, the largest psoriasis patient advocacy organization and charitable funder of psoriatic disease research worldwide, exists to find a cure for psoriasis and psoriatic arthritis. Psoriasis, the Nation's most prevalent autoimmune disease, affecting as many as 7.5 million Americans, is a noncontagious, chronic, inflammatory, painful and disabling disease for which there is no cure. It is a systemic disease that appears on the skin, most often as red, scaly patches that itch, can bleed and require sophisticated medical intervention. Up to 30 percent of people with psoriasis also develop potentially disabling psoriatic arthritis that causes pain, stiffness and swelling in and around the joints. There are other serious risks associated with psoriasis—for example, diabetes, cardiovascular disease, stroke and some cancers. Of serious concern is that beyond its terrible physical and psychosocial toll on individuals, psoriasis costs the Nation \$11.25 billion annually.

From an epidemiology standpoint, psoriasis and psoriatic arthritis in the U.S. population is poorly understood. We do not yet understand the natural history of these diseases, how it affects various populations differently, and how real-world treatments impact disease progression. Much of the current understanding of psoriasis epidemiology comes from databases from other countries such as the United Kingdom or Denmark. However, these populations differ significantly from those in the U.S. with regards to patient demographics, environmental factors and practice and treatment patterns.

In an effort to address these gaps in understanding, the Foundation works with the Nation's research community and policymakers at all levels of Government to advance policies and programs that will reduce and prevent suffering from psoriasis and psoriatic arthritis. In 2009, after examining existing scientific literature, clinical practice and other components of psoriasis and psoriatic arthritis research and care, the Foundation's medical and scientific advisors recommended the creation of a federally-organized public health research program for psoriasis and psoriatic arthritis to collect the information necessary to address the key scientific questions in the study and treatment of psoriatic disease. Responding to this recommendation, recognizing the significant economic and social costs of psoriasis and psoriatic arthritis and acknowledging the sizeable gap in the understanding of these challenging conditions, in fiscal year 2010, Congress provided \$1.5 million to CDC to commence an effort to identify what gaps exist. CDC has been an excellent steward of this Federal funding, working diligently to develop a public health agenda for psoriasis while stretching these dollars over the course of three fiscal years.

Thanks to the initial Congressional appropriation, on February 12, 2013, the CDC released the first-ever public health agenda designed to address psoriasis and psoriatic arthritis. The agenda, entitled *Developing and Addressing the Public Health Agenda for Psoriasis and Psoriatic Arthritis*, was developed by CDC in collaboration with clinical, biomedical and public health experts. Working in partnership, these

experts identified gaps and developed a list of priorities to be addressed by future psoriasis and psoriatic arthritis research efforts. The identified priorities include:

- Improving the way psoriasis and psoriatic arthritis are diagnosed.
- Examining the relationship between other chronic diseases or comorbidities with psoriasis and psoriatic arthritis.
- Examining how people with psoriatic diseases access health care, the cost of their treatments and how the diseases impact their ability to work.
- Studying the effect of psoriasis and psoriatic arthritis on quality of life and other outcomes.

Investing in these priority areas of study will generate much-needed public health data that will help scientists understand the underlying questions about psoriatic diseases and how they affect a large population of people, and, in turn, this insight will help identify the most promising areas of new research to find better treatments and move the Nation closer to a cure.

As such, we respectfully request that Congress continue to support this important initiative by appropriating \$1.2 million in fiscal year 2014 to enable the NCHS within the CDC to begin to answer the pressing questions identified in the psoriasis and psoriatic arthritis public health agenda. Federally funded efforts are critical to determine epidemiology of psoriasis and psoriatic arthritis in Americans, the associated comorbidities, and impact of treatments in the U.S. With fiscal year 2014 funding, NCHS will be able to develop and validate relevant and meaningful questions specific to psoriasis and psoriatic arthritis. With rigorous sampling methods and survey administration, we will be able to obtain valuable information from a nationally representative population to determine the natural history of psoriasis and psoriatic arthritis in the U.S. population, the effect of environmental factors on disease progression, the impact and comorbidities, and the effect of treatments on psoriasis patient outcomes.

THE IMPACT OF PSORIASIS AND PSORIATIC ARTHRITIS ON THE NATION

Psoriasis requires steadfast treatment and lifelong attention. People with psoriasis have significantly higher health care resource utilization, which costs more than that of the general population. As noted earlier, of serious and increasing concern is mounting evidence that people with psoriasis are at elevated risk for other serious, chronic and life-threatening conditions, including cardiovascular disease and diabetes. In addition, people with psoriasis experience higher rates of depression and anxiety, and they die 4 years younger, on average, than people without the disease.

Despite some recent breakthroughs, many people with psoriasis and psoriatic arthritis remain in need of effective, safe, long-term and affordable therapies to allow them to function without both physical and emotional pain. Due to the nature of the disease, patients often have to cycle through available treatments, and while there are an increasing number of methods to control the disease, there is no cure. Many of the existing treatments can have serious side effects and can pose long-term risks for patients (e.g., suppress the immune system, deteriorate organ function, etc.). The lack of viable, long-term methods of control for psoriasis can be addressed through a robust Federal commitment to epidemiological, genetic, clinical and basic research. Research holds the key to improved treatment and diagnosis of psoriatic disease and, eventually, a cure.

THE ROLE OF CDC IN PSORIASIS AND PSORIATIC ARTHRITIS RESEARCH

Despite our increased understanding of the autoimmune underpinnings of psoriasis and its treatments, there is a dearth of population-based epidemiology data on psoriatic disease. Broadly-representative population-based studies of psoriasis reflecting the full spectrum of disease are lacking and much-needed because there are still wide gaps in our knowledge and understanding of psoriatic disease. CDC's implementation of the psoriasis and psoriatic arthritis public health agenda will help to provide scientists and clinicians with critical information to further their understanding of (a) how early intervention can prevent or delay the development of comorbid conditions; (b) what factors can trigger flares and remissions; (c) some of the underlying causes of disease; (d) how differentiating lifestyle and other environmental triggers might lead to approaches that minimize exposure to these factors, thus reducing the incidence and severity of disease; and (e) best practice treatments, which would assist in improving patient care and outcomes, and in turn, help reduce health care costs.

PSORIASIS AND PSORIATIC ARTHRITIS RESEARCH AT NIH

It has taken nearly 30 years to understand that psoriasis is, in fact, not solely a disease of the skin, but also of the immune system. Recently, scientists identified some of the immune cells involved in psoriasis, and over the last decade we have seen a surge in the understanding of these diseases, accompanied by new drug development. Scientists are poised, as never before, to make major breakthroughs; to facilitate such advancements, we need increased investment in the National Institutes of Health (NIH).

Within the NIH, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is the principal Federal Government agency that supports psoriasis research. We commend NIAMS for its leadership role and very much appreciate its steadfast commitment to supporting and advancing psoriasis research. Additionally, we are pleased that research activities that relate to psoriasis or psoriatic arthritis also have been undertaken within other NIH institutes and centers; this work is critical given the myriad comorbidities of psoriasis, as noted earlier. We advocate a strong Federal investment in genetic, immunological and clinical studies focused on understanding the mechanisms of psoriasis and psoriatic arthritis be funded and maintained.

Given the myriad factors involved in psoriatic disease and its comorbid conditions, the Foundation urges Congress to boost funding for NIH and NIAMS. We recognize the Nation faces significant budgetary challenges; however, we believe an increased Federal investment in biomedical research will help strengthen the economy and our understanding of psoriatic disease.

CONCLUSION/SUMMARY

On behalf of the more than 7.5 million people with psoriasis and psoriatic arthritis, I thank the subcommittee for the opportunity to submit written testimony regarding the fiscal year 2014 investments we believe are necessary to ensure that our Nation adequately addresses the needs of individuals and families affected by psoriatic disease. By allocating \$1.2 million to implement CDC's psoriasis and psoriatic arthritis public health agenda, Congress will help ensure that the Nation makes progress in understanding the connection between psoriasis and its comorbid conditions, uncovering the biologic aspects of psoriasis and other risk factors that lead to higher rates of comorbid conditions and identifying ways to prevent and reduce the onset of comorbid conditions associated with psoriasis. Please feel free to contact the Foundation at any time; we are happy to be a resource to subcommittee members and your staff.

PREPARED STATEMENT OF NATIONAL PUBLIC RADIO

Dear Chairman Harkin, Senator Moran and members of the subcommittee: My name is Gary E. Knell, and I am the President and CEO. Thank you for this opportunity to urge the subcommittee's support for an annual Federal investment of \$445 million in public broadcasting through the Corporation for Public Broadcasting (CPB). With your support, every American will continue to have free access to the best in news, information, educational and cultural programming.

As the President and CEO of National Public Radio (NPR), I offer this testimony on behalf of the public radio system, a uniquely American public service, non-for-profit media enterprise that includes NPR, other producers and distributors of public radio programming including American Public Media (APM), Public Radio International (PRI), the Public Radio Exchange (PRX), and our more than 950 public radio station partners, both large and small, that create and distribute content through the Public Radio Satellite System (PRSS).

Funding provided by Congress to the CPB supports the entire foundation of a system that has been one of America's most successful models of a community-centric grant program. The cost of public broadcasting is only 0.01 percent of the entire Federal budget. The revenue base provided by Congress enables stations to raise \$6 for every Federal grant dollar. This Federal financial investment permits local stations to invest more deeply in their own local news and cultural programming which in turn enables our stations to provide the American public with an enduring and daily return on investment that is heard, seen, read, and experienced in public radio broadcasts, apps, podcasts, and online.

With support from the CPB's community service grants, each of the hundreds of independently-operated public radio stations creates and curates the mix of programs that best meets the needs of their local community. These stations and their programming choices are as diverse as the people who live in the communities they

serve. Some have all-news formats. Others have all-music formats. Others create a blend of news, talk, commentary and music into their program offerings. Close to thirty percent of our stations' daily programming is locally generated. Every year the Federal Government invests roughly ninety million dollars in the operation of America's local public radio stations, and these stations in turn provide service to all of America's congressional districts and States.

In our congressional testimony last year, we highlighted three essential contributions of public radio to Americans: our deeply rooted local community connections from which all staffing, management and programming decisions are made; public radio's significant and growing contributions to music and local music economies; and public radio's indispensable role as a lifeline information source during times of local and regional crises.

These unique contributions remain clearly in view as public radio adjusts to America's changing demographics and undergoes renewal to accommodate the demands of our audience and the opportunities presented by the march of technology.

Mr. Chairman, 2013 marks the twelfth year of armed overseas conflict, the longest period of sustained warfare in United States history. Some 2.3 million Americans have now served in the wars in Iraq and Afghanistan, with more than thirty-two thousand casualties, and tens of thousands more enduring the mental strains of combat. Now, with the military drawdown taking place, these men and women are returning home, with many facing difficult transitions. NPR and its public radio station partners are delving deeply into the lives of America's veterans to foster an understanding of the impact of war to the public and to policymakers. Unique and dedicated reporting projects like StoryCorps' Military Voices Initiative allow the stories and lives of America's veterans to be heard and preserved. We believe that illuminating these stories will deepen the connections between our Nation's civilian population and military communities.

When the storm clouds of Hurricanes Isaac and most recently Sandy gathered, so did the reporters of local public radio stations and NPR. Stations in the affected areas worked nonstop to deliver updates on damage, relief assistance, and places of refuge and safety. The public radio system worked together to bring these local struggles and challenges to a national audience.

The work of New York Public Radio (WNYC) perfectly illustrates all of public radio's commitment to nonstop coverage during emergencies and crises. Despite losing power to its Lower Manhattan headquarters on the evening Sandy struck, and later its AM transmitter in New Jersey, WNYC stayed on the air with an emergency generator to provide the critical news and information its local citizens needed. Its news websites, wnyc.org and njpublicradio.org, operated on back-up servers to provide up-to-date news and information, such as its interactive maps that tracked transit options, flooding and power outages. More than 4.6 million visitors came to its sites for Sandy information.

Public radio's coverage following the terrorist bombing attacks at the Boston Marathon is another example of the extraordinary power and reach of our local-national system based on stations. By using our programming interconnection system, Boston-based WBUR's coverage was available to all Americans through their local public radio stations.

The station's round-the-clock coverage is best understood in the following summary by Charles Kravitz, General Manager of WBUR, who shared this with his station colleagues after that horrible week:

"As I'm sure you agree WBUR simply did its job, as any of you have done and will do when a major story develops in your community. That's why we are here. We were writing 'the first rough draft of history' that will no doubt be refined and examined for years to come. All of your kind words buoyed us when our energy sagged at the end of some long days.

"The city of Boston was the real hero of this story. Countless stories, large and small, of sacrifice and bravery, of loss and grief, painted a tapestry of this complex and beautiful city that many of us had not seen before. Tragedy, as you know, will do that. People held hands, strangers hugged each other and children sang songs which uplifted us. Out of something terrible came something beautiful.

"It is in this moment that I am reminded of how fortunate I am, how fortunate we all are, to do the work we do and to serve the public in such a vital and important way. However imperfect we are, we make a difference. It is gratifying."

Public radio's commitment to bring news to all Americans during emergency events is also reflected in a recent award from the U.S. Department of Homeland Security (DHS) and the Federal Emergency Management Agency (FEMA) to NPR Labs. This contract will enable the demonstration of delivering emergency alerts to

deaf or hard-of-hearing communities in Gulf Coast States through local public radio stations and the PRSS. This is the first-ever effort to deliver real-time accessibility-targeted emergency messages, such as weather alerts, through radio broadcast texts.

Mississippi Congressman Steven Palazzo commented on this activity by saying:

“As we work to promote disaster preparedness and awareness, it is important we remember to equip every member of our communities. This valuable partnership with Mississippi’s local public radio stations promises to expand the reach of our disaster alert systems, and I can think of no better place to conduct this trial than the Gulf Coast.”

We are committed to bringing the breadth of America’s diverse voices to our programs so that our audience has the benefit of hearing the full rundown of ideas, thoughts and policy perspectives that populate our country’s political, cultural and social conversation. Capturing the diversity of these conversations, including political, age, racial, ethnic and geographic, is at the center of our mission to serve as America’s public radio.

A further commitment to exploring and serving the changing nature of America’s citizens can be found in our newly launched initiative on race, ethnicity and culture. With support from the CPB, NPR has formed a new team of six journalists to identify and report on news and issues of race and ethnicity, thus presenting new voices that define an increasingly diverse America.

And lastly, Mr. Chairman, at a time when most other American news organizations are drawing down on their commitments to cover international news, NPR is growing its overseas presence. From Mexico City to Berlin, from Shanghai to Dakar, NPR correspondents based in eighteen foreign bureaus bring listeners dynamic stories of the world’s people, politics, economies, and cultures. Our reporters live in these areas and are on the ground for breaking news and in-depth, ongoing coverage of foreign policy and national security events.

NPR has permanent bureaus throughout the Middle East in order to fully represent the impact of the region: Islamabad, Istanbul, Kabul, Beirut, and Jerusalem. Correspondents based in these five cities, along with those in Cairo, New Delhi, and Jakarta, bring to life the experiences of people in war-torn regions, keep an eye on U.S. military engagements abroad, and cover civil uprisings and regime changes.

Recently, the work of Kelly McEvers and Deborah Amos collected the highest honors in journalism, the DuPont-Columbia and Peabody Awards, for their coverage of the Syrian conflict. Their recognition truly reflects the work of many in what is a total team effort. McEver’s stories were edited and overseen by senior staff. Show producers carefully mixed the stories and the NPR web team wrote compelling text and found perfect photographs to illustrate them. This is but a single sampling of an ongoing labor of devotion and professional dedication by intrepid journalists who are committed to sharing the world’s stories, events and people with America.

Mr. Chairman and Senator Moran, NPR and the public radio system are committed to being America’s public radio where rational, fact-based, accurate and civil reporting and conversation are our top priorities. We have no political agenda and we do not take sides. Public radio plays an important, significant and growing role in news, journalism, and music and cultural programming. Our stations are essential to, and part of, the communities they serve.

Public radio stations are reaching audiences wherever they are. We’re embracing America’s changing demographics and using digital media to connect better, more quickly and in more diverse ways. Today’s public radio isn’t going away, it’s going everywhere—and we are working every day to earn the trust of the thirty-eight million Americans who rely on us for news and insights that guide and inform.

PREPARED STATEMENT OF THE NATIONAL RESPITE COALITION

Mr. Chairman, I am Jill Kagan, Chair of the National Respite Coalition (NRC), a network of respite providers, family caregivers, national, State and local agencies and organizations who support respite. Thirty State respite coalitions are also affiliated with the NRC. This statement is presented on behalf of these organizations. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 200 national, State and local groups who support the Lifespan Respite Program and its continued funding. We are requesting that the subcommittee include \$2.5 million for the Lifespan Respite Care Program administered by ACL/AoA in the fiscal year 2014 Labor, HHS, and Education Appropriations bill. This amount, very slightly above current sequestration levels, is the same amount appropriated each year since 2009 and the amount requested by the President in his fiscal year 2014 budget proposal. This will enable:

- State replication of best practices in Lifespan Respite to allow all family caregivers, regardless of the care recipient's age or disability, to have access to affordable respite, and to be able to continue to play the significant role in long-term care that they are fulfilling today;
- Improvement in the quality of respite services currently available;
- Expansion of respite capacity to serve more families by building new and enhancing current respite options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

WHO NEEDS RESPITE?

In 2009, about 61.6 million family caregivers provided care at some time during the year. The estimated economic value of their unpaid contributions was approximately \$450 billion. This amount is more than total 2009 Medicaid spending, including both Federal and State contributions for health care and long-term services and supports (\$361 billion). Including caregiving for children with special needs in the total would add at least 4 to 8 million additional caregivers and another \$50 to \$100 billion to the economic value of family caregiving (Feinberg, L.; Reinhard, S., et al. Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving, AARP Public Policy Institute, 2011).

Family caregiving is not just an aging issue, but also a lifespan one. While the aging population is growing rapidly, the majority of family caregivers are caring for someone under age 75 (56 percent); 28 percent of family caregivers care for someone between the ages of 50–75, and 28 percent care for someone under age 50 (National Alliance for Caregiving (NAC) and AARP, 2009). Many family caregivers are in the sandwich generation—46 percent of women who are caregivers of an aging family member and 40 percent of men also have children under the age of 18 at home (Aumann, Kerstin and Ellen Galinsky, et al. 2008). And 6.7 million children are in the primary custody of an aging grandparent or other relative.

Families of the wounded warriors, military personnel who returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions, don't have full access to respite. Even with enactment of the new VA Family Caregiver Support Program, the need for respite will remain high for all veterans and their family caregivers. Caregivers whose veterans have PTSD are about half as likely as other caregivers to receive respite (11 percent vs. 20 percent) (NAC, Caregivers of Veterans—Serving On the Homefront, November 2010). Sixty-eight percent of veterans' caregivers reported their situation as highly stressful compared to 31 percent of caregivers nationally, and three times as many say there is a high degree of physical strain (40 percent vs. 14 percent) (NAC, 2010). Veterans' caregivers specifically asked for up-to-date lists of respite providers in their communities and help to find services, the very thing Lifespan Respite is charged to provide (NAC, 2010).

National, State and local surveys have shown respite to be the most frequently requested service of the Nation's family caregivers (The Arc, 2011; National Family Caregivers Association, 2011). Other than financial assistance for caregiving through direct vouchers payments or tax credits, respite is the number one national policy related to service delivery that family caregivers prefer (NAC and AARP, 2009). Yet respite is unused, in short supply, inaccessible, or unaffordable to a majority of the Nation's family caregivers. The NAC 2009 survey found that despite the fact that among the most frequently reported unmet needs of family caregivers were "finding time for myself" (32 percent), "managing emotional and physical stress" (34 percent), and "balancing work and family responsibilities" (27 percent), nearly 90 percent of family caregivers across the lifespan are not receiving respite services at all.

An estimated 80 percent of all long-term care in the U.S. is provided at home. This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living with their aging parents or other caregivers, the aging of the baby boom generation, and the decline in the percentage of the frail elderly who are entering nursing homes.

RESPITE BARRIERS AND THE EFFECT ON FAMILY CAREGIVERS

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. Even when respite is an allowable funded service, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need. Lifespan Respite is designed to

help States eliminate these barriers through improved coordination and capacity building.

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers experience physical and emotional problems directly related to their caregiving responsibilities. In a 2009 survey of family caregivers, a majority (51 percent) who are caring for someone over age 18 have medium or high levels of burden of care, measured by the number of activities of daily living with which they provide assistance, and 31 percent were identified as “highly stressed” (NAC and AARP, 2009). While family caregivers of children with special health care needs are younger than caregivers of adults, they give lower ratings to their health. Caregivers of children are twice as likely as the general adult population to say they are in fair/poor health (26 percent vs. 13 percent) (Provisional summary Health Statistics for US Adults, National Health Interview Survey, 2008, dated August 2009).

The decline of family caregiver health is one of the major risk factors for institutionalization of a care recipient, and there is evidence that care recipients whose caregivers lack effective coping styles or have problems with depression are at risk for falling, developing preventable secondary complications such as pressure sores and experiencing declines in functional abilities (Elliott & Pezent, 2008). Care recipients may also be at risk for encountering abuse from caregivers when the recipients have pronounced need for assistance and when caregivers have pronounced levels of depression, ill health, and distress (Beach et al., 2005; Williamson et al., 2001).

Supports that would ease family caregiver stress, most importantly respite, are too often out of reach or completely unavailable. Restrictive eligibility criteria also preclude many families from receiving services or continuing to receive services for which they once were eligible. Children with disabilities will age out of the system when they turn 21 and they will lose many of the services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) conducted by The Arc found: the vast majority of caregivers report that they are suffering from physical fatigue (88 percent), emotional stress (81 percent) and emotional upset or guilt (81 percent) some or most of the time; 1 out of 5 families (20 percent) report that someone in the family had to quit their job to stay home and support the needs of their family member; and more than 75 percent of family caregivers caring for adult children with developmental disabilities could not find respite services (The Arc, 2011). Respite may not exist at all in some States for individuals with Alzheimer’s, those under age 60 with conditions such as ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions.

RESPITE BENEFITS FAMILIES AND IS COST SAVING

Respite has been shown to be an effective way to reduce stress and improve the health and well-being of family caregivers that in turn helps avoid or delay out-of-home placements, such as nursing homes or foster care, minimizes the precursors that can lead to abuse and neglect, and strengthens marriages and family stability. A new study of parents of children with autism spectrum disorders found that respite care was associated with reduced stress and improved marital quality (Harper, Amber, et al, 2013). A U.S. Department of Health and Human Services report prepared by the Urban Institute found that higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry. Reducing key stresses on caregivers, such as physical strain and financial hardship, through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). In a recent survey of caregivers of individuals with Multiple Sclerosis (MS), two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent (NAC, 2012).

The budgetary benefits that accrue because of respite are just as compelling. Delaying a nursing home placement for just one individual with Alzheimer’s or other chronic condition for several months can save Medicaid and other Government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every \$1,000 States spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization (Mandell, David S., et al, 2012). In the private sector, the Metropolitan Life Insurance Company and the National Alliance for Caregivers found that U.S. businesses lose from \$17.1 billion to \$33.6 billion per year in lost productivity of family caregivers (MetLife and National Alliance for Caregiving, 2006). Respite for working

family caregivers could help improve job performance and employers could potentially save billions.

LIFESPAN RESPITE CARE PROGRAM WILL HELP

The Federal Lifespan Respite program is administered by the Administration for Community Living (ACL), Administration on Aging (AoA), U.S. Department of Health and Human Services (HHS). ACL/AoA provides competitive grants to eligible State agencies in concert with Aging and Disability Resource Centers working in collaboration with State respite coalitions or respite organizations. Congress appropriated \$2.5 million each year from fiscal year 2009–fiscal year 2012 and a slightly lower amount due to sequestration in fiscal year 2013. Since 2009, thirty States and the District of Columbia have received three-year \$200,000 Lifespan Respite Grants from AoA. Nine States and DC received one-time \$150,000 expansion grants to focus on direct services, especially for those who are unserved. Last year, seven of the original 2009 grantees received 17-month Integration and Sustainability grants to continue their important work.

The purpose of the law is to expand and enhance respite services, improve coordination, and improve respite access and quality. States are required to establish State and local coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in gaining access to services. Those eligible would include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond that required by children generally to meet basic needs.

Lifespan Respite, defined as a coordinated system of community-based respite services, helps States use limited resources across age and disability groups more effectively. Provider pools can be recruited, trained and shared, administrative burdens reduced by coordinating resources, and savings used to fund new respite services for families who do not qualify for any Federal or State program.

HOW IS LIFESPAN RESPITE PROGRAM MAKING A DIFFERENCE?

With limited funds, Lifespan Respite grantees are engaged in innovative activities such as:

- In TN and RI, the Lifespan Respite program is building respite capacity by expanding volunteer networks of providers by recruiting University students or Senior Corps volunteers or expanding the national TimeBanks model for establishing voluntary family cooperative respite strategies.
- In Texas, the Lifespan Respite program has established a statewide Respite Coordination Center, and an online database.
- In SC, the State respite coalition and the Lifespan Respite program are partnering in new ways with the untapped faith community to provide respite, especially in rural areas.
- The North Carolina Lifespan Respite Program has challenged each of its 100 counties to improve respite service delivery locally, and has partnered with the Money Follows the Person program to develop family caregiver peer-to-peer support and respite.
- In NH, new providers have been recruited and trained through partnerships with the NH National Alliance on Mental Illness, New Hampshire Family Voices, and the College of Direct Support with funding from the Department of Labor to expand the pool of respite providers to work with teens and older individuals with mental health conditions or other groups where respite is in short supply.
- The AZ Lifespan Respite program housed in Division of Aging and Adult Services has partnered with their State's Children with Special Health Care Needs Program to provide respite vouchers to families in need across the age and disability spectrum.
- The OK Lifespan Respite program partnered with their State's Federal Transit Administration's Section 5310 transportation authority to release a van no longer needed by the program to transport respite volunteers and materials to isolated rural areas to provide respite in church and community center social halls.

Across the board, States are building respite registries and “no wrong door systems” in collaboration with State respite coalitions and Aging and Disability Resource Centers to help family caregivers access respite and funding sources. OK, AL, NV, TN and others are using Lifespan Respite grants to expand or implement participant-directed respite through coordinated voucher systems so that family care-

givers have greater control over the type and quality of the respite they select. All State grantees secure commitments from partnering State agencies to share information and coordinate resources to build a seamless Lifespan Respite system for accessing respite.

Funding must be maintained to help sustain these impressive and innovative State efforts. The goal of Lifespan Respite System is to coordinate respite services and funding, maximize existing resources and leverage new dollars in both the public and private sectors to build respite capacity and serve the unserved, but States need more time and fiscal support to do so. Maintaining funding for the program in fiscal year 2014 could allow several new States to start Lifespan Respite Programs and help assist at least a few of the remaining grantees to complete the work that they have started. As it is, given the limited funding for fiscal year 2013, only 3–5 new States are expected to be funded and only up to five of the original twenty-four 2009 and 2010 grantees will be funded. Most will be cut off before they have had a chance to make a lasting impact.

No other Federal program mandates respite as its sole focus. No other Federal program helps ensure respite quality or choice, and no current Federal program allows funds for respite start-up, training or coordination or to address basic accessibility and affordability issues for families. We urge you to include at least \$2.5 million in the fiscal year 2014 Labor, HHS, Education appropriations bill so that Lifespan Respite Programs can be replicated and sustained in the States and more families, with access to respite, will be able to continue to play the significant role that they are fulfilling today.

PREPARED STATEMENT OF THE NATIONAL SENIOR SERVICE CORPS

Mr. Chairman, Members of the Committee, my name is Gary Goosman and I am Senior Programs Director of the Corporation for Ohio Appalachian Development. I testify today on behalf of the National Senior Corps Association, representing the interests and ideals of more than 400,000 senior volunteers and the directors, staff, and friends of local Foster Grandparent, Senior Companion, and RSVP programs throughout the country.

For fiscal year 2014, NSCA requests \$110,565,000 for the Foster Grandparent Program (FGP), \$69,300,000 for RSVP (restoring the 20 percent that was cut in fiscal year 2010), and \$46,722,000 for the Senior Companion Program (SCP). This level of funding will provide for continued support for existing grantees and competition for new grantees. Our request is composed of the following goals:

- Support for Continuing Services—\$244,986,540 (FGP—\$110,565,000; RSVP—\$69,300,000; SCP—\$46,722,000). These grant funds allow existing Senior Corps programs and the nearly 400,000 volunteers to continue providing critical services, including:
 - Independent living services. SCP volunteers provide companionship and support needed to help frail seniors remain independent and in their own homes at a cost lower than institutional care. RSVP volunteers provide a range of services to frail elders and people with disabilities, and respite to caregivers to help preserve independent living and reduce costly institutionalization.
 - Mobilizing volunteers. RSVP volunteers recruit or manage additional community volunteers to serve in local communities.
 - Serving children and vulnerable families. FGP volunteers tutor children with low literacy skills and mentor troubled teenagers and young mothers. RSVP volunteers tutor thousands of children, and steer disadvantaged children and youth toward a more productive and responsible path.
 - Assisting in disaster preparedness and recovery. Often the first national service participants to respond, RSVP volunteers staff emergency kitchens and shelters, distribute food and clothing, and assist in relocating affected individuals and families.
 - Assisting with clean energy programs. RSVP volunteers provide home-based services such as weatherization and handyman assistance to families in need of extra support.
- Stipend—even though the Kennedy Serve America Act authorizes the increase in the Federal stipend (for Foster Grandparents and Senior Companions) from \$2.65 to \$3.00 per hour we realize that these are difficult economic times and we would defer this increase until future budgets have the capacity to include a stipend increase.
- Silver Scholarships. While current legislation does not exclude Senior Corps volunteers from receiving Silver Scholarships, it does not specifically state that they are included. NSCA requests allowing flexibility in rule interpretation to

allow Senior Corps program eligibility for Silver Scholarships. Silver Scholarships are \$1,000 transferable education awards for adults age 55 and older who serve 350 hours per year. The award may be given to their child or grandchild. NSCA requests \$1,000,000 for Silver Scholarships.

SENIOR CORPS is a federally authorized and funded network of national service programs that provides older Americans with the opportunity to apply their life experiences to volunteer service. Senior Corps is comprised of the Foster Grandparent Program, RSVP, and the Senior Companion Program, through which Americans age 55 and older provide essential services to cost-effectively address critical community needs.

Foster Grandparent Program.—27,900 Foster Grandparents in 325 projects provide a cost-effective means to reach and support more than 232,000 at-risk children with special or exceptional needs annually who otherwise may not have the opportunity to receive individual assistance and attention from a caring adult. In 2011, Foster Grandparents volunteered over 24 million hours.

- 81 percent of children served demonstrated improvements in academic performance. Mentored children have reduced truancy resulting in reduced school costs and, ultimately, reduced high school dropout rates and increased lifetime earnings.

- 90 percent demonstrated increased self-image. This includes improved health outcomes such as reductions in teen pregnancy and reduced or delayed use of tobacco, alcohol, or illicit drugs.

- 56 percent reported improved school attendance leading to increased graduation rates, increased post-secondary education, and higher lifetime earnings.

- 59 percent reported reduction in risky behavior, including reduced juvenile violence and property crimes, saving victim and court expenses, costly treatment of juvenile offenders, costs of adult crime, crime losses of victims and the societal costs of prosecuting and incarcerating adult offenders.

In 2011, FGP volunteers mentored more than 232,000 children and youth, of which 5,400 were children of prisoners at high risk of repeating their parent's path. FGP intervention reduced need for social services, both short-term costs of counseling and long-term costs of public assistance.

Based on conservative assumptions about outcomes and valuations, studies indicate a return benefit of \$2.72 for every dollar of resources used for mentoring programs. (Analyzing the Social Return on Investment in Youth Mentoring Programs, prepared by: Paul A. Anton, Wilder Research; and Prof. Judy Temple, University of Minnesota).

Foster Grandparent Program Profiles.—Ethel Goss turned 92 years old this past January. Before beginning the program in 2010 she had retired from a receptionist position at a local daycare. When she called to inquire about the program she had stated that she was bored and needed to be with children. Kinsey Tumblin Head Start teacher) writes, "I have to admit there was a little concern about her age, but she reassured me that she walked with a cane only because her son made her! Once I met with Ethel those concerns completely disappeared; I found her to be quick, alert and full of compassion. As I anxiously waited to see the assignment plans and progress reporting, it was not a surprise to me that it was very good news." Grandma Ethel had two children assigned to her, one 3 year old and one 4 year old. The 4 year old needed individual help with fine motor skills, interaction with familiar adults, building appropriate vocabulary for obtaining wants, and to gain positive communication skills. By May, with the one-on-one mentoring from Grandma Ethel all goals were met, including the programmatic goal for Head Start Programs.

RSVP.—296,100 RSVP volunteers contributed 62 million hours of service in 2011 through 685 projects nationwide working with more than 65,000 community organizations. The average cost to support one RSVP volunteer is approximately \$145 a year, whereas the average annual value per volunteer is more than \$3,000. RSVP volunteers saved local communities more than \$1.25 billion in 2011.

RSVP is continually strengthening its leadership role in engaging volunteers 55+ by providing nonprofit agencies with volunteers trained to recruit and coordinate other community members in support of the nonprofits mission and goals. In 2011, RSVP volunteers recruited 38,000 additional community volunteers.

RSVP projects demonstrate that their volunteer services increase literacy scores for the more than 80,000 children they mentor—the National Education Association states the lowest hourly rate for teacher aides is \$10.31 reflecting a savings of \$16,858,623 in remedial reading assistance.

- 25,000 RSVP volunteers increased the capacity of the organizations where they serve by enhancing both the quality and quantity of services.

- In 2011, RSVP volunteers mentored 16,200 children of prisoners at high risk of repeating their parent's path.

—RSVP volunteers provided 23,300 caregivers with respite services. A recent AARP survey of working caregivers reports that 30 percent of family caregivers either quit their jobs or reduce their work hours to take on more care giving responsibilities.

—RSVP volunteers supported 509,000 with Independent Living Services.

—30 percent of RSVP volunteers provided at least one service in the area of Health/Nutrition which includes in-home and congregate meals, food distribution/collection, immunization, etc. valued at more than \$27 million.

Senior Companion Program.—13,600 Senior Companions serving in 194 projects provided 12.2 million hours of service helping 60,940 frail, homebound clients in need of assistance in order to remain living independently. If all those individuals were instead served in Assisted Living facilities it would be at a cost of \$2,289,637,680. Senior Companion Program services prevented premature and costly institutionalization at an annual savings well over \$2 billion. The national average cost for 1 year in a nursing home is \$72,270; the assisted living facility yearly average cost is \$37,572. One Senior Companion volunteer assists 2–6 homebound clients for the annual investment of \$4,800.

Senior Companions offered essential respite to nearly 9,000 primary caregivers who struggle to remain in the regular workforce while caring for their loved one. The Family Caregiver Alliance reports that families with long-term care responsibilities miss an average of 7.5 workdays each year.

The MetLife Caregiving Cost Study of July 2006 reports the estimated cost to employers of full-time employed intense caregivers at a total of \$17.1 billion in lost productivity annually as well as absenteeism, workday interruptions, costs due to crisis in care, supervision costs associated with caregiver employees, costs with unpaid leave and reducing hours from full-time to part-time.

Clients have significant, long-term mental health benefits and reduced rates of depression saving \$50–\$75 a month in medication.

Cost of stress management therapy for one caregiver (\$125 per session) vs. respite provided by volunteer (4 hours of respite care = \$10.60 plus mileage average cost of \$3).

Cost for a home health aide after a client's release from the hospital is \$21 per hour as compared to \$2.65 per hour for a Senior Companion volunteer (at no cost to clients).

Senior Companion Program Profile.—Jane H. is in the beginning stages of Alzheimer's but still has some of her memory. She has a Senior Companion named Barb. She says Barb is a huge help and provides personal comfort to her so that she is not alone. Both of her kids work and she has no one available thru the day. She is always afraid of falling because she is a little clumsy. Her daughter, Sue, is Director of the Friendship Center in Carrollton. Sue explained that, "...having Barb there gives me a great peace of mind while I'm at work. Our county has limited services and home visitors aren't available." She further said, "My brother has a full time job as well and all of his family works during the day." The family takes turns in the evening hours with Jane. "Mom doesn't want to be in a nursing home so this program allows her to stay in her apartment. This is where she is happiest".

It has been stated that baby boomer and senior volunteers represent our Nation's single and fastest growing resource. During this unprecedented economic crisis facing our Nation, the number of baby boomer and senior volunteers should be greatly expanded and mobilized as solutions to the problems facing our local communities. NSCA's 2014 budget request will provide the opportunity for thousands more older adults to serve in their communities and enhance the lives of those most in need, including children with special needs, the frail and isolated elderly striving to maintain independence, and expanding the services of local non-profit agencies.

The 2012 national value of one hour of volunteer service was estimated at \$22.14.

Senior Corps volunteers' 98.2 million service hours in 2012 = \$2.174 billion savings

NSCA recommendations on Re-competition.—While the National Senior Corps Association supports the level of funding for Senior Corps in the President's 2014 budget, we also express concern regarding language to institute re-competition in the Senior Companion and Foster Grandparent, and changes the authorized language for RSVP as set forth in the Edward M Kennedy Serve America Act. The National Senior Corps Association embraces and supports the concept of re-competition for Senior Corps grants, we feel strongly the responsibility of changing the law governing the Senior Corps programs rests with the Authorizing committee. We respectfully request that none of the funds in this Act may be used to administer re-competition of Senior Corps programs, except as authorized by the Edward M Kennedy Serve America Act as enacted.

Senior Corps Program	Fiscal Year 2012 Enacted	Fiscal Year 2013 President's Requested	Fiscal Year 2013 Enacted	Fiscal Year 2014 President's Request	Fiscal Year 2014 NSCA Request
Foster Grandparent Program (FGP)	\$110,565,000	\$110,565,000	\$111,241,000	\$110,565,000	\$110,565,000
RSVP	50,204,200	50,299,000	50,511,000	50,204,000	69,300,000
Senior Companion Program (SCP)	46,722,000	46,810,000	47,007,000	46,722,000	46,722,000

PREPARED STATEMENT OF THE NATIONAL TECHNICAL INSTITUTE FOR THE DEAF
(NTID)

Mr. Chairman and Members of the Committee: My name is Dr. Gerard J. Buckley, and I am the President of NTID, and the Vice President and Dean of RIT. I am pleased to present the fiscal year 2014 budget request for NTID, one of nine colleges of RIT, in Rochester, N.Y. Created by Congress by Public Law 89-36 in 1965, we provide university technical and professional education for students who are deaf and hard-of-hearing, leading to successful careers in high-demand fields for a subpopulation of individuals historically facing high rates of unemployment and underemployment. We also provide baccalaureate and graduate level education for hearing students in professions serving deaf and hard-of-hearing individuals. NTID students live, study and socialize with more than 16,000 hearing students on the RIT campus.

Budget Request

On behalf of NTID, for fiscal year 2014 I would like to request \$67,422,000 in Operations. I make this request within the context of definitive actions taken by NTID to recognize the difficult economic times in which we operate. In fiscal year 2012 and the first half of fiscal year 2013, NTID operated with essentially the same level of Federal support as in fiscal year 2011. In order to manage level funding, we significantly reduced equipment purchases and eliminated 37 positions—a workforce reduction of 6 percent in the midst of record enrollments. We have also reduced our budget by an average of 8 percent in such areas as building and equipment maintenance, instructional supplies, freelance interpreting, professional travel and student employment. For several years now, NTID has also postponed requests for construction funding for critical and long overdue renovations to a 30-year old building currently housing three times the number of staff for which it was intended. We have continued to increase tuition and fees, as these are our primary sources of non-Federal support. From fiscal year 2006 to fiscal year 2013, tuition and fees have increased by 49 percent to offset the rising costs of providing a state-of-the-art college education. These non-Federal revenues now represent 27 percent of our operating budget—up from 9 percent in 1970. Likewise, from fiscal year 2006 to fiscal year 2012, NTID raised almost \$19 million in support from individuals and organizations.

Our request of \$67,422,000 for Operations would help us balance our budget and reduce the damage we have incurred from sequestration. It is important to note that this request for fiscal year 2014 is only 3.2 percent more than the fiscal year 2011 operating appropriation and significantly reduced from our original request of \$73,819,000 (including \$2,000,000 for construction) submitted to the Department of Education in June 2012. Despite the measures we have taken to manage level funding, the 5.23 percent reduction from sequestration is requiring us to make further cuts in the areas of equipment purchasing, interpreting and captioning, scholarship support, building maintenance, and, most importantly, in personnel and enrollment. If the 5.23 percent reduction stands, we will have to undertake a workforce reduction of up to 54 filled positions (about 10 percent of our current headcount). This reduction in staff could result in denying as many as 240 qualified deaf and hard-of-hearing students from enrolling each year. These are not the consequences a successful Federal investment should face.

Enrollment

Truly a national program, NTID has enrolled students from all 50 States. Applications for enrollment in fiscal year 2013 (Fall 2012) were up 9 percent, as we experienced one of the highest enrollments in our history—1,529 students. Over the last 7 years, our enrollment has increased 22 percent. For fiscal year 2014, NTID hopes to maintain this high enrollment, if our operational resources allow us to do so. Our enrollment history over the last 7 years is shown below:

NTID ENROLLMENTS: FISCAL YEAR 2007–FISCAL YEAR 2013

Fiscal Year	Deaf/Hard-of-Hearing Students				Hearing Students			Grand Total
	Undergrad	Grad RIT	MSSE	Sub-Total	Interpreting Program	MSSE	Sub-Total	
2007	1,017	47	31	1,095	130	25	155	1,250
2008	1,103	51	31	1,185	130	28	158	1,343
2009	1,212	48	24	1,284	135	31	166	1,450
2010	1,237	38	32	1,307	138	29	167	1,474
2011	1,263	40	29	1,332	147	42	189	1,521
2012	1,281	42	31	1,354	160	33	193	1,547
2013	1,269	37	25	1,331	167	31	198	1,529

MSSE: Master of Science in Secondary Education of Deaf/Hard of Hearing Students.

Grad RIT: other graduate programs at RIT.

NTID Academic Programs

NTID offers high quality, career-focused associate degree programs preparing students for specific well-paying technical careers. NTID also is expanding the number of its transfer associate degree programs to better serve the higher achieving segment of our student population seeking bachelor's and master's degrees. These transfer programs provide seamless transition to baccalaureate studies in the other colleges of RIT. In support of those deaf and hard-of-hearing students enrolled in the other RIT colleges, NTID provides a range of access services (including interpreting, real-time speech-to-text captioning, and notetaking) as well as tutoring services. One of NTID's greatest strengths is our outstanding track record of assisting high-potential students to gain admission to, and graduate from, the other colleges of RIT at rates comparable to their hearing peers.

A cooperative education (co-op) component is an integral part of academic programming at NTID and prepares students for success in the job market. A co-op gives students the opportunity to experience a real-life job situation and focus their career choice. Students develop technical skills and enhance vital personal skills such as teamwork and communication, which will make them better candidates for full-time employment after graduation. Almost 300 students last year participated in 10-week co-op experiences that augment their academic studies, refine their social skills, and prepare them for the competitive working world.

Student Accomplishments

For our graduates, over the past 5 years, an average of 91 percent have been placed in jobs commensurate with the level of their education. Of our fiscal year 2011 graduates (the most recent class for which numbers are available), 54 percent were employed in business and industry, 31 percent in education/non-profits, and 15 percent in Government.

Graduation from NTID has a demonstrably positive effect on students' earnings over a lifetime, and results in a notable reduction in dependence on Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In fiscal year 2012, NTID, the Social Security Administration, and Cornell University examined earnings and Federal program participation data for more than 15,000 deaf and hard-of-hearing individuals who applied to NTID over our entire history. The studies show that NTID graduates over their lifetimes are employed at a much higher rate, earn substantially more (therefore paying significantly more in taxes), and participate at a much lower rate in SSI and SSDI than students who withdrew from NTID.

Using SSA data, at age 50, 78 percent of NTID deaf and hard-of-hearing graduates with bachelor degrees and 73 percent with associate degrees report earnings, compared to 58 percent of NTID deaf and hard-of-hearing students who withdrew from NTID. Equally important is the demonstrated impact of an NTID education on graduates' earnings. At age 50, \$58,000 is the median salary for NTID deaf and hard-of-hearing graduates with bachelor degrees and \$41,000 for those with associate degrees, compared to \$34,000 for deaf and hard-of-hearing students who withdrew from NTID. Higher earnings, of course, yield higher tax revenues.

An NTID education also translates into reduced dependency on Federal transfer programs, such as SSI and SSDI. At age 40, less than 2 percent of NTID deaf and hard-of-hearing associate and bachelor degree graduates participate in the SSI program compared to 8 percent of deaf and hard-of-hearing students who withdrew from NTID. Similarly, at age 50, only 18 percent of NTID deaf and hard-of-hearing bachelor degree graduates and 28 percent of associate degree graduates participate

in the SSDI program, compared to 35 percent of deaf and hard-of-hearing students who withdrew from NTID.

Access Services

NTID provides an access services system to meet the needs of a large number of deaf and hard-of-hearing students enrolled in baccalaureate and graduate degree programs in RIT's other colleges as well as students enrolled in NTID programs who take courses in the other colleges of RIT. Access services also are provided for events and activities throughout the RIT community. Access services include sign language interpreting, real-time captioning, classroom notetaking services, captioned classroom video materials, and Assistive Listening Services.

As enrollments have steadily increased, so has the demand for access services. In fiscal year 2012, 129,900 hours of interpreting were provided—an increase of 14 percent compared to fiscal year 2008. In fiscal year 2012, 19,516 hours of real-time captioning were provided to students—a 17 percent increase over fiscal year 2008. The increase in demand is partly a result of the increase in the number of students enrolled in baccalaureate programs at RIT and the number of students with cochlear implants. In fiscal year 2013, there were 551 deaf and hard-of-hearing students enrolled in baccalaureate programs at RIT, a 22 percent increase compared to fiscal year 2008, and 356 students with cochlear implants—a 40 percent increase over fiscal year 2008.

Summary

It is extremely important that our fiscal year 2014 funding request be granted in order that we might continue our mission to prepare deaf and hard-of-hearing people to enter the workplace and society. NTID has shown through hard data that our graduates have higher salaries, pay more taxes, and depend less on Federal SSI/SSDI payments than their counterparts who do not attend NTID. Our employment rate is 91 percent over the past 5 years—even more remarkable given the state of the economy. Demand for an NTID education is higher than ever. Therefore, I ask that you please consider funding our request of \$67,422,000 for Operations.

We are hopeful that the Members of the Committee will agree that NTID, with its long history of successful stewardship of Federal funds and outstanding educational record of service with people who are deaf and hard-of-hearing, remains deserving of your support and confidence. Likewise, we will continue to demonstrate to Congress and the American people that NTID is a proven economic investment in the future of young deaf and hard-of-hearing citizens. Quite simply, NTID is a Federal program that works.

PREPARED STATEMENT OF THE NATIONAL VIOLENCE PREVENTION NETWORK

Thank you for this opportunity to submit testimony in support of increased funding for the National Violent Death Reporting System (NVDRS), which is administered by the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention (CDC). The National Violence Prevention Network, a broad and diverse alliance of health and welfare, suicide and violence prevention, and law enforcement advocates supports increasing the fiscal year 2014 funding level to \$25 million to allow for nationwide expansion of the NVDRS program. fiscal year 2013 NVDRS funding is \$3.5 million.

Background

Each year, about 55,000 Americans die violent deaths. Suicide and homicide are the fourth and fifth leading causes of death for Americans of all ages. In addition, an average of 105 people (22 of which are military veterans) take their own lives each day.

The NVDRS program makes better use of data that are already being collected by health, law enforcement, and social service agencies. The NVDRS program, in fact, does not require the collection of any new data. Instead it links together information that, when kept in separate compartments, is much less valuable as a tool to characterize and monitor violent deaths. With a clearer picture of why violent deaths occurs, law enforcement, public health officials and others can work together more effectively to identify those at risk and target effective preventive services.

Currently, NVDRS funding levels only allow the program to operate in 18 States, including Alaska, Colorado, Georgia, Kentucky, Maryland, Massachusetts, Michigan, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Utah, Virginia, and Wisconsin. Six additional States; Connecticut, Illinois, Maine, Minnesota, New York, and Texas plus the District of Columbia, were previously approved for participation in the NVDRS, but were unable to join due

to funding shortfalls. Several other States have expressed an interest in joining once new funding becomes available. While NVDRS is beginning to strengthen violence and suicide prevention efforts in the 18 participating States, non-participating States continue to miss out on the benefits of this important public health surveillance program.

NVDRS in Action

Child abuse and other violence involving children and adolescents remains a problem in America, and it is only through a comprehensive understanding of its root causes that these needless deaths can be prevented. Studies suggest that between 3.3 and 10 million children witness some form of domestic violence annually. Additionally, 1,560 children died as a result of abuse or neglect in 2010.

Children are most vulnerable and most dependent on their caregivers during infancy and early childhood. Sadly, NVDRS data has shown that young children are at greatest risk of homicide in their own homes. Combined NVDRS data from Alaska, Maryland, Massachusetts, New Jersey, Oregon, South Carolina, and Virginia determined that African American children aged 4 years old and under are more than four times more likely to be victims of homicide than Caucasian children, and that homicides of children aged four and under are most often committed by a parent or caregiver in the home. The data also shows that household items, or “weapons of opportunity,” were most commonly used, suggesting that poor stress responses may be factors in these deaths. Knowing the demographics and methods of child abusers can lead to more effective, targeted prevention programs.

Intimate partner violence (IPV) is another issue where NVDRS is proving its value. While IPV has declined along with other trends in crime over the past decade, thousands of Americans still fall victim to it every year. Intimate partner homicides accounted for 30 percent of the murders of women and 5 percent of the murders of men in 2006, according to the Bureau of Justice Statistics.

Despite being in its early stages in several States, NVDRS is already providing critical information that is helping law enforcement and public health officials allocate resources and develop programs in ways that target those most at risk for intimate partner violence. For example, NVDRS data shows that while occurrences are rare, most murder-suicide victims are current or former intimate partners of the suspect, and a substantial number of victims were the suspect’s children. In addition, NVDRS data indicate that women are about seven times more likely than men to be killed by a spouse, ex-spouse, lover, or former lover, and most of these incidents occurred in the women’s homes.

NVDRS & VA Suicides

Although it is preventable, every year more than 38,000 Americans die by suicide and another one million Americans attempt it, costing more than \$36 billion in lost wages and work productivity. In the United States today, there is no comprehensive national system to track suicides. However, because NVDRS includes information on all violent deaths—including deaths by suicide—information from the system can be used to develop effective suicide prevention plans at the community, State, and national levels.

The central collection of this data can be of tremendous value for organizations such as the Department of Veterans Affairs that are working to improve their surveillance of suicides. For instance, CDC determined from national NVDRS data that veterans comprised 20 percent of all suicide victims. The types of data collected by NVDRS including gender, blood alcohol content, mental health issues, physical health issues, and intimate partner violence can help prevention programs better identify and treat at-risk individuals.

Federal Role Needed

At an estimated annual cost of \$25 million for full implementation, NVDRS is a relatively low-cost program that yields high-quality results. While State-specific information provides enormous value to local public health and law enforcement officials, data from all 50 States, the U.S. territories and the District of Columbia must be obtained to complete the national picture. Aggregating this additional data will allow us to analyze national trends and also more quickly and accurately determine what factors can lead to violent death so that we can devise and disseminate strategies to address those factors.

Strengthening and Expanding NVDRS in Fiscal Year 2014

In January 2013, President Obama and Vice President Biden released, “Now Is The Time: The President’s Plan to Protect our Children and our Communities by Reducing Gun Violence.” Recognizing the utility of NVDRS in understanding vio-

lence, one of the major strategies in the report calls for an infusion of \$20 million for NVDRS to facilitate its nationwide expansion.

The National Violence Prevention Network, a coalition of national organizations that advocate for national violence prevention programs, is supporting the Administration's request by calling on Congress to provide \$25 million for NVDRS in fiscal year 2014. As State funding is based on population and violent death rates, significant funding increases are necessary to incorporate larger States into the program. However, the cost of not implementing the program is much greater: without national expansion of the program, thousands of American lives remain at risk.

We thank you for the opportunity to submit this statement for the record. The investment in NVDRS has already begun to pay off as the 18 participating States are adopting effective violence prevention programs. We believe that national implementation of NVDRS is a wise public health investment that will assist State and national efforts to prevent deaths from domestic violence, veteran suicide, teen suicide, gang violence and other violence that affects communities around the country. We look forward to working with you secure an fiscal year 2014 NVDRS appropriation of \$25 million.

PREPARED STATEMENT OF NEMOURS

Nemours thanks Chairman Harkin, Ranking Member Moran and members of the subcommittee for the opportunity to submit written testimony on the fiscal year 2014 Labor, Health & Human Services, Education and Related Agencies Appropriations bill. Nemours, one of the Nation's leading child health systems, is dedicated to improving children's health and well-being by offering a spectrum of clinical treatment, research, advocacy, educational health, and prevention services extending to families in the communities it serves.

About Nemours

Nemours is an internationally recognized children's health system that owns and operates the Alfred I. duPont Hospital for Children in Wilmington, Delaware, along with major pediatric specialty clinics in Delaware, Florida, Pennsylvania and New Jersey. In October 2012, we opened the full-service Nemours Children's Hospital in Orlando, Florida. The Nemours promise is to do whatever it takes to treat every child as we would our own. We are committed to making family-centered care the cornerstone of our health system.

Established as The Nemours Foundation through the legacy and philanthropy of Alfred I. duPont, Nemours offers pediatric clinical care, research, education, advocacy and prevention programs to families in the communities we serve. We leverage our entire system to improve the health of our communities by creating unique models, creating new points of access and delivering superlative outcomes. Our investment in children is a response to community health needs as Nemours aims to fulfill our mission to provide leadership, institutions and services to restore and improve the health of children through care and programs not readily available.

Community-based Prevention

As an integrated health system that is very engaged with the community, Nemours sees first-hand the impact of chronic disease on our Nation's children. We treat obese young children at our clinics, and we know that unhealthy habits that contribute to obesity are starting at a very young age. In fact, over twenty-seven percent of children ages 2-5 are obese or overweight—an alarming statistic. We know that much of what influences their health is outside the realm of the health care system, which is why we have made and will continue to make significant investments in community-based prevention, in sectors where children learn, live, and play. We believe that investing in clinical and community-based prevention is an important way to ensure that children grow up to be healthy adults. The Prevention and Public Health Fund (Fund) holds the potential to address obesity and chronic disease and ultimately reduce our Nation's health care costs over a lifetime.

We are mindful of the continued efforts to make significant cuts to the Fund. However, we believe strongly that crucial elements of health care reform and prevention should not be pitted against one another. For example, physicians must be enlisted in the fight to prevent disease and should be working closely with other community-based partners to help families and children lead healthy, active lifestyles, as is the case with Nemours-employed physicians. We urge the Committee to utilize the resources provided from the Fund to support the integration of clinical and community-based prevention and to evaluate the outcomes associated with those investments.

The National Early Childcare and Education Learning Collaboratives (CDC)

The National Early Childcare and Education (ECE) Learning Collaboratives program is uniquely focused on working with early child care and education providers to help children eat healthy and be physically active.

As one of the Nation's leading child health organizations, with significant expertise impacting local, State and national obesity prevention initiatives in early care and education settings, Nemours and its partners, including the National Initiative for Children's Healthcare Quality, Child Care Aware of America, American Academy of Pediatrics, and other strategic partners in ECE and public health, will implement evidence-based, practice-tested learning collaboratives in partnership with six States—Arizona, Florida, Indiana, Kansas, Missouri, and New Jersey—reaching over 400,000 children over the course of the five-year project.

Ultimately, the goal is to spread impactful, sustainable program-level changes to transform early childcare and education programs. In particular, continued funding for the ECE project will help early-care and education providers (initially ECE centers, and later family child care settings as well) in these six States adopt nutrition, breastfeeding support, physical activity, and screen time policies and practices.

Through the ECE project, Nemours and its partners also will create a new resource, the National ECE Technical Assistance and Support Center for Quality Improvement (National TA Center) to provide targeted support to the learning collaboratives and participating programs and support quality improvement capacity within State ECE systems to promote additional spread and sustainability.

As a Nation, we face daunting economic and fiscal challenges. To a large degree, these challenges are driven by high health care costs. Preventable chronic diseases account for approximately 75 percent of our Nation's annual \$2.5 trillion in health care spending. We believe Federal investment in approaches that help instill healthy habits early in a child's life can help bring down these costs. For these reasons, we urge the subcommittee to provide \$4.2 million for the ECE program in fiscal year 2014, which is consistent with the fiscal year 2012 funding level for the program.

Children's Hospital Graduate Medical Education (HRSA)

Another important priority for Nemours is the health care workforce, particularly the pediatric workforce. Children's hospitals care for large numbers of children with highly complex medical needs. Cutting edge, superior quality clinical care requires that hospitals invest time and resources in training residents on how to provide the best, most-effective treatments for this population. The Children's Hospital Graduate Medical Education program (CHGME) provides support for graduate medical education to freestanding children's hospitals that train resident physicians. The CHGME program helps address shortages in the pediatric workforce in both general (primary care) pediatrics and in pediatric sub-specialties.

The CHGME program has increased the number of pediatric providers, addressed critical shortages in pediatric specialty care, and improved children's access to care. CHGME ensures that general pediatricians and pediatric specialists are trained to care for children in communities across the country—metropolitan cities, rural communities, suburbs and everywhere in between—covering everything from well-child visits to the most complex cardiac surgeries. Today, the children's hospitals that receive CHGME, less than 1 percent of all hospitals, train more than 49 percent of general pediatricians and 51 percent of pediatric specialists.

Over 300 residents are trained each year at the Alfred I. duPont Hospital for Children (AIDHC) in Wilmington, DE. They are on the front line for families at our hospital, caring for patients 24 hours a day. They are also training to become future clinicians who will practice independently in general pediatrics specialties and sub-specialties. In the outpatient department, they become the primary care physicians (under attending supervision) for numerous children. Residents are also learning to become researchers and are actively engaged in local community and international volunteer efforts to reach medically-underserved children.

Unfortunately, the President's fiscal year 2014 budget request once again proposes reducing funding for this program to \$88 million. We urge Congress to reject this ill-advised cut and to continue providing adequate support for training the next generation of pediatricians, pediatric specialists and pediatric researchers. In fiscal year 2014, Nemours urges the subcommittee to provide funding at the fully-authorized level of \$317.5 million. However, in this difficult fiscal environment, we urge that funding for the CHGME program not dip below \$265.2 million, which was the level prior to sequester.

Conclusion

Nemours appreciates the opportunity to submit written testimony. As an integrated child health system, we have prioritized investments in clinical and community-based prevention and our workforce because we believe that in the long-run these investments will improve health for children and bend the health care cost curve. We recognize that the Nation's fiscal situation requires a close examination of the programs and priorities that the Federal Government funds. As you make these critical funding decisions, we hope that prevention and the future health care workforce will remain priorities of the subcommittee in fiscal year 2014.

PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2014

- 1) \$32 billion for the National Institutes of Health (NIH) and a corresponding increase to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).
 - 2) Continued support for the Grants for Research in Glomerular Diseases Initiative and the Advancing Clinical Research in Primary Glomerular Diseases Program at NIDDK, as well as the Nephrotic Syndrome Study Network at the Office of Rare Diseases Research (ORDR).
 - 3) Expansion of the FSGS/NS Research Portfolio at NIDDK, the Office of Rare Diseases Research (ORDR) and the National Institute on Minority Health and Health Disparities (NIMHD) by funding more research proposals for Primary Glomerular Disease.
-

Thank you for the opportunity to present the views of the NephCure Foundation regarding research on idiopathic focal segmental glomerulosclerosis (FSGS) and primary nephrotic syndrome (NS). NephCure is the only non-profit organization exclusively devoted to fighting FSGS and the NS disease group. Driven by a panel of respected medical experts and a dedicated band of patients and families, NephCure works tirelessly to support kidney disease research and awareness.

NS is a collection of signs and symptoms caused by diseases that attack the kidney's filtering system. These diseases include FSGS, Minimal Change Disease and Membranous Nephropathy. When affected, the kidney filters leak protein from the blood into the urine and often cause kidney failure, which requires dialysis or kidney transplantation. According to a Harvard University report, 73,000 people in the United States have lost their kidneys as a result of FSGS. Unfortunately, the causes of FSGS and other filter diseases are poorly understood.

FSGS is the second leading cause of NS and is especially difficult to treat. There is no known cure for FSGS and current treatments are difficult for patients to endure. These treatments include the use of steroids and other dangerous substances which lower the immune system and contribute to severe bacterial infections, high blood pressure and other problems in patients, particularly child patients. In addition, children with NS often experience growth retardation and heart disease. Finally, NS caused by FSGS, MCD or MN is idiopathic and can often reoccur, even after a kidney transplant.

FSGS disproportionately affects minority populations and is five times more prevalent in the African American community. In a groundbreaking study funded by NIH, researchers found that FSGS is associated with two APOL1 gene variants. These variants developed as an evolutionary response to African sleeping sickness and are common in the African American patient population with FSGS/NS.

FSGS has a large social impact in the United States. FSGS leads to end-stage renal disease (ESRD) which is one of the most costly chronic diseases to manage. In 2008, the Medicare program alone spent \$26.8 billion, 7.9 percent of its entire budget, on ESRD. In 2005, FSGS accounted for 12 percent of ESRD cases in the U.S., at an annual cost of \$3 billion. It is estimated that there are currently approximately 23,000 Americans living with ESRD due to FSGS.

Research on FSGS could achieve tremendous savings in Federal health care costs and reduce health status disparities. For this reason, and on behalf of the thousands of families that are significantly affected by this disease, we encourage support for expanding the research portfolio on FSGS/NS at the NIH.

Encourage FSGS/NS Research at NIH

There is no known cause or cure for FSGS and scientists tell us that much more research needs to be done on the basic science behind FSGS/NS. More research

could lead to fewer patients undergoing ESRD and tremendous savings in health care costs in the United States.

With collaboration from other Institutes and Centers, ORDR established the Rare Disease Clinical Research Network. This network provided an opportunity for the NephCure Foundation, the University of Michigan, and other university research health centers to come together to form the Nephrotic Syndrome Study Network (NEPTUNE). NEPTUNE is developing a database of NS patients who are interested in participating in clinical trials which would alleviate the problem faced by many rare disease groups of not having access to enough patients for research. NephCure urges the subcommittee to continue its support for RDCRN and NEPTUNE, which has tremendous potential to facilitate advancements in NS and FSGS research.

The NephCure Foundation is also grateful to NIDDK for issuing program announcements (PA) that serve to initiate grant proposals on primary glomerular disease. Two PAs that have recently been issued utilize the R01 and UM1 mechanisms to award funding for primary glomerular disease research. NephCure recommends the subcommittee encourage NIDDK to continue to issue primary glomerular disease PAs.

Due to the disproportionate burden of FSGS on minority populations, it is appropriate for NIMHD to develop an interest in this research. NephCure asks the subcommittee to encourage ORDR, NIDDK and NIMHD to collaborate on research that studies the incidence and cause of this disease among minority populations. NephCure also asks the subcommittee to urge NIDDK and the NIMHD to undertake culturally appropriate efforts aimed at educating minority populations about primary glomerular disease.

Thank you again for the opportunity to present the views of the FSGS/NS community. Please contact the NephCure Foundation if additional information is required.

PREPARED STATEMENT OF THE NEUROFIBROMATOSIS (NF) NETWORK

Thank you for the opportunity to submit testimony to the subcommittee on the importance of continued funding at the National Institutes of Health (NIH) for research on Neurofibromatosis (NF), a genetic disorder closely linked to many common diseases widespread among the American population.

We respectfully request that you include the following report language on NF research at the National Institutes of Health within your fiscal year 2014 Labor, Health and Human Services, Education Appropriations bill.

Neurofibromatosis [NF].—The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, and NF preclinical mouse models consortia. The Committee urges NHLBI to expand its NF research investment based on the increased prevalence of hypertension and congenital heart disease in this patient population. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair, learning disabilities and attention deficit disorders. In addition, the Committee encourages the NICHD and NIMH to expand funding of basic and clinical NF research in the area of learning and behavioral disabilities. Children with NF1 are prone to severe bone deformities, including scoliosis; the Committee therefore encourages NIAMS to expand its NF1 research portfolio. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research. Based on the increased incidence of optic gliomas, vision loss, cataracts, and retinal abnormalities in NF, the Committee urges the NEI to expand its NF research portfolio. Finally, given that NF represents a tractable model system to study the genomics of cancer predisposition, learning and behavior problems, and bone abnormalities translatable to individualized medicine, the Committee encourages NHGRI to increase its investment in NF research.

On behalf of the Neurofibromatosis (NF) Network, a national organization of NF advocacy groups, I speak on behalf of the 100,000 Americans who suffer from NF as well as approximately 175 million Americans who suffer from diseases and conditions linked to NF such as cancer, brain tumors, heart disease, memory loss, and learning disabilities. Thanks in large measure to this subcommittee's strong support, scientists have made enormous progress since the discovery of the NF1 gene

in 1990 resulting in clinical trials now being undertaken at NIH with broad implications for the general population.

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and even death. In addition, approximately one-half of children with NF suffer from learning disabilities. NF is the most common neurological disorder caused by a single gene and three times more common than Muscular Dystrophy and Cystic Fibrosis combined. There are three types of NF: NF1, which is more common, NF2, which primarily involves tumors causing deafness and balance problems, and schwannomatosis, the hallmark of which is severe pain. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live with the uncertainty of not knowing whether they will be seriously affected because NF is a highly variable and progressive disease.

Researchers have determined that NF is closely linked to heart disease, learning disabilities, memory loss, cancer, brain tumors, and other disorders including deafness, blindness and orthopedic disorders, primarily because NF regulates important pathways common to these disorders such as the RAS, cAMP and PAK pathways. Research on NF therefore stands to benefit millions of Americans:

Pain Management

Severe and unmanageable pain is seen in all forms of NF, particularly in schwannomatosis, and significantly impacts quality of life. Over the past 3 years, Schwannomatosis research has made significant advances and new research suggests that the molecular or root cause of schwannomatosis pain may be the same as phantom limb pain. Understanding what causes this pain, and how it might be treated, has been a fast-moving area of NF research over the past few years, and CDMRP NFRP funding has been critical in supporting this.

Nerve regeneration

NF often requires surgical removal of nerve tumors, which can lead to nerve paralysis and loss of function. Understanding the changes that occur in a nerve after surgery, and how it might be regenerated and functionally restored, will have significant quality of life value for affected individuals.

Wound Healing, inflammation and blood vessel growth

Wound healing requires new blood vessel growth and tissue inflammation. Mast cells are critical mediators of inflammation in wound healing, and they must be quelled and regulated in order to facilitate this healing. Mast cells are also important players in NF1 tumor growth. In the past few years, researchers have gained deep knowledge on how mast cells promote tumor growth, and this research has led to ongoing clinical trials to block this signaling. The result is that tumors grow slower. As researchers learn more about blocking mast cell signals in NF, this research could be translated to the management of mast cells in wounds and wound healing.

Bone growth and repair/Orthopedic abnormalities and amputation

At least a quarter of children with NF1 have abnormal bone growth in any part of the skeleton. In the legs, the long bones are weak, prone to fracture and unable to heal properly; this can require amputation at a young age. Adults with NF1 also have low bone mineral density, placing them at risk of skeletal weakness and injury. NF1 bone defects research has been a fast-moving field in recent years and CDMRP NFRP has funded a number of important studies in this area.

Brain Function/Learning Disabilities

Learning disabilities affect two-thirds of person with NF1, ranging from mild to severe, and including attention and social behavior deficits. Learning disabilities impact the quality of life for those with NF1 more than tumors or any other clinical feature. In recent years, research has revealed common threads between NF1 learning disabilities, autism and other related disabilities.

The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. The enormous promise of NF research, and its potential to benefit over 175 million Americans who suffer from diseases and conditions linked to NF, has gained increased recognition from Congress and the NIH. This is evidenced by the fact that eleven institutes are currently supporting NF research, and NIH's total NF research portfolio has increased from \$3 million in fiscal year 1990 to an estimated \$24 million in fiscal year 2012. Given the potential offered by NF research for progress against a range of diseases, we are hopeful that the NIH will continue to build on the successes of this program

by funding this promising research and thereby continuing the enormous return on the taxpayers' investment.

We appreciate the subcommittee's strong support for NF research and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued. Thank you.

PREPARED STATEMENT OF THE NURSING COMMUNITY

The undersigned organizations representing the Nursing Community, a forum comprised of 58 national professional nursing associations, respectfully submit this testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. The Nursing Community works collaboratively to build consensus and advocate on a wide spectrum of healthcare and nursing issues surrounding practice, education, and research. Our organizations are committed to promoting America's health through the advancement of the nursing profession. Collectively, the Nursing Community represents nearly one million registered nurses (RNs), advanced practice registered nurses (APRNs-including certified nurse-midwives, nurse practitioners, clinical nurse specialists, and certified registered nurse anesthetists), nurse executives, nursing students, nursing faculty, and nurse researchers.

For fiscal year 2014, the Nursing Community respectfully requests \$251 million for the Health Resources and Services Administration's (HRSA) Nursing Workforce Development programs (authorized under Title VIII of the Public Health Service Act [42 U.S.C. 296 et seq.]), \$150 million for the National Institute of Nursing Research (NINR, one of the 27 centers and institutes of the National Institutes of Health), and \$20 million in authorized funding for the Nurse-Managed Health Clinics (NMHCs, Title III of the Public Health Service Act). These investments are critical to ensuring that high-quality nursing services are delivered nationwide.

The Demand for Nursing Continues to Outgrow Supply

The U.S. Bureau of Labor Statistics (BLS) projects that the total number of additional nurses will rise dramatically. In its report *Employment Projections: 2010–2020*, the BLS reveals that the expected number of practicing nurses will grow from 2.74 million in 2010 to 3.45 million in 2020, an increase of 712,000 or 26 percent. The projections further explain the need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020.

Two primary factors contribute to this overwhelming projection. First, America's nursing workforce is aging. According to the 2013 HRSA report *The U.S. Nursing Workforce: Trends in Supply and Demand*, of the 2.8 million RNs currently practicing in our Nation, 34.9 percent are over the age of 50, and 8.5 percent are over the age of 60. As the economy continues to rebound, many of these nurses will seek retirement, leaving behind a significant deficit in the number of experienced nurses in the workforce. Secondly, America's Baby Boomer population is aging. It is estimated that over 80 million Baby Boomers reached age 65 last year. This population will require a vast influx of nursing services, particularly in areas of primary care and chronic illness management.

Concurrently, tens of thousands of qualified applicants are turned away from nursing school each year. According to the American Association of Colleges of Nursing's 2012–2013 survey on enrollment and graduations, 79,659 qualified applications were turned away from entry-level baccalaureate and graduate nursing programs in 2012 alone. Nursing schools report that faculty vacancies, alongside a lack of funding and clinical training sites, are a primary reason that prevents schools from maximizing student enrollment. Moreover, a special survey on nursing faculty vacancy conducted by AACN for the 2012–2013 academic year reveals an average vacancy rate of 7.6 percent for full-time positions and 6.8 percent for part-time positions within baccalaureate and graduate nursing programs across the country.

A significant investment must be made in the education of new nurses to provide the Nation with the nursing services it demands.

How Title VIII Nursing Workforce Development Programs Support the Supply of Nurses

For nearly five decades, the Nursing Workforce Development programs have helped build the supply and distribution of qualified nurses to meet our Nation's healthcare demands. The Title VIII programs support nursing education at all levels, and are designed to address specific needs of patient populations as well as those within the nursing workforce.

These programs are vital to expediting the number of nurses entering into the workforce pipeline. AACN's 2012–2013 Title VIII Student Recipient Survey, which gathers information about Title VIII dollars and their impact on nursing students, demonstrates that Title VIII programs played a critical role in persuading students to enroll in nursing school. This survey, which included responses from over 1,100 students, reveals that 74 percent of the respondents receiving Title VIII funding are currently attending school full-time. By supporting full-time students, these programs help to ensure that students enter the workforce without delay.

Lastly, Title VIII programs help increase access to care in areas experiencing shortages in the number of health professionals and health services. The Title VIII Student Recipient Survey reveals that nearly 21 percent of student respondents intend to practice in a community hospital, and 22.7 percent of respondents plan to practice in public health or in a rural or underserved area upon graduation. Furthermore, many of these students also report that due to Title VIII assistance, they are able to pursue a career in geographic areas where salary is not as competitive, but where the demand for nursing services is great.

The Nursing Community respectfully requests \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014.—The Nursing Community recognizes that Congress is faced with difficult decisions surrounding Federal deficit reduction, however we believe this amount is critical in ensuring the nursing workforce can meet the national demand for nursing services.

Advancing Nursing Science through the National Institute of Nursing Research

Research conducted at the NINR contributes to the advancement of nursing science that is translated into evidence-based practice. Initiatives funded through NINR center around increasing health promotion, reducing rates of chronic illness and transmissible disease, and improving patient quality of life. More specifically, NINR investigates unique ways to integrate the patient experience into health practices that empower patients and their families toward these goals. This includes efforts to improve symptom management related to chronic disease, reduce suffering at the end of life, and understand how genomics impact disease processes for specific populations. While other healthcare research focuses on curing disease, a large portion of NINR's work is aimed at preventing disease. This work is fundamental to our healthcare system's endeavor of providing high-quality care in a cost-effective manner by mitigating burdensome costs associated with treatment.

Moreover, NINR helps to provide needed faculty to support the education of future generations of nurses. Training programs at NINR develop future nurse-researchers, many of whom also serve as faculty in our Nation's nursing schools.

—The Nursing Community respectfully requests \$150 million for the NINR in fiscal year 2014.

Nurse-Managed Health Clinics: Expanding Access to Care

Run by an APRN and staffed by an interdisciplinary team, NMHCs provide essential primary care services in communities across the country. These clinics are often associated with a school, college, university, department of nursing, federally qualified health center, or independent nonprofit healthcare agency. NMHCs can be found in medically underserved regions of the country, including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. Nurses and other health professionals who work in NMHCs serve as educators to patients and their families by teaching healthy lifestyle practices and promoting disease prevention. By providing early assessment and intervention for patients who are often most vulnerable to co-morbidities, NMHCs help manage medical conditions that have the potential to transpire into acute events. As a result, NMHCs help patients out of the emergency room, thereby improving patient outcomes and saving the healthcare system millions of dollars annually.

Furthermore, NMHCs serve as clinical education training sites for nursing students and other health professionals—a crucial aspect of NMHCs given that a lack of training sites is commonly identified as a barrier to nursing school enrollment. An increasing emphasis on interdisciplinary care delivery necessitates that health professionals begin their training in an environment conducive to collaborative work. Many NMHCs serve as clinical training sites for nurses, physicians, social workers, public health nurses, and therapists to foster patient-centered care early on in their practice.

—The Nursing Community respectfully requests \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2014.

Without a workforce of well-educated nurses providing evidence-based care to those who need it most, including our growing aging population, the healthcare system is not sustainable. The Nursing Community's request of \$251 million for the Title VIII Nursing Workforce Development programs, \$150 million for the National Institute of Nursing Research, and \$20 million for Nurse-Managed Health Clinics in fiscal year 2014 will help ensure access to quality care provided by America's nursing workforce.

MEMBERS OF THE NURSING COMMUNITY SUBMITTING THIS TESTIMONY

Academy of Medical-Surgical Nurses	Hospice and Palliative Nurses Association
American Academy of Ambulatory Care Nursing	Infusion Nurses Society
American Academy of Nursing	International Association of Forensic Nurses
American Association of Colleges of Nursing	International Society of Psychiatric Nursing
American Association of Nurse Anesthetists	National Association of Clinical Nurse Specialists
American Association of Nurse Practitioners	National Association of Neonatal Nurse Practitioners
American College of Nurse-Midwives	National Association of Neonatal Nurses
American Nephrology Nurses' Association	National Association of Nurse Practitioners in Women's Health
American Nurses Association	National Association of Pediatric Nurse Practitioners
American Organization of Nurse Executives	National Black Nurses Association
American Pediatric Surgical Nurses Association	National Nursing Centers Consortium
American Society for Pain Management Nursing	National Organization for Associate Degree Nursing
American Society of PeriAnesthesia Nurses	National Organization of Nurse Practitioner Faculties
Association of Community Health Nursing Educators	Oncology Nursing Society
Association of Nurses in AIDS Care	Pediatric Endocrinology Nursing Society
Association of periOperative Registered Nurses	Preventive Cardiovascular Nurses Association
Association of Public Health Nurses	Public Health Nursing Section, American Public Health Association
Association of Rehabilitation Nurses	Society of Urologic Nurses and Associates
Commissioned Officers Association of the U.S. Public Health Service	The Quad Council of Public Health Nursing Organizations
Dermatology Nurses' Association	Wound, Ostomy and Continence Nurses Society
Gerontological Advanced Practice Nurses Association	

PREPARED STATEMENT OF THE NURSE PRACTITIONER ROUNDTABLE

Chairman Harkin, Ranking Member Moran, and members of the subcommittee: The Nurse Practitioner Roundtable is comprised of the five nurse practitioner associations representing the interests and concerns of the more than 155,000 nurse practitioners (NPs) across the country. Our organizations advocate for the active role of NPs as providers of high quality, cost-effective, comprehensive, patient-centered healthcare and their patients. NPs have been furnishing primary, acute and specialty healthcare to patients of all ages and walks of life for nearly half a century. They assess the health care needs of patients; order, perform, supervise, and interpret diagnostic tests; make diagnoses; and initiate and manage treatment plans including prescribing medications. They are the healthcare providers of choice for millions of patients. More than 80 percent of NPs are educationally prepared as family, adult, gerontologic, pediatric, and women's health primary care providers.

NPs work with organizations representing the rest of the advanced practice registered nurse (APRN) and general nursing community to support a strong Federal investment in the Nursing Workforce Development programs, to secure authorized funding for Nurse-Managed Health Clinics, and fund research initiatives at the National Institute of Nursing Research (NINR) to ensure that a sufficient supply of the highest-quality nursing services is available to meet the Nation's increasing need for effective and efficient healthcare.

The Growing Demand for Nurse Practitioners

As millions of Americans enroll in expanded health insurance coverage in 2014, our Nation will face a dramatically increased demand for health care providers at a time when many professions face shortages and increasing retirements. Policy makers recognize that NPs are essential to meeting the demand for primary care services for women, children, the uninsured and patients with special needs, yet we face a provider shortage that is projected to continue. A significant and sustained investment in the education of NPs is needed to produce the workforce required to meet our population's demands for health care services.

Nursing education programs are under increased pressure as Congress wrestles with reducing the Federal deficit. The six-month continuing resolution (H.J. Res. 117) enacted last September extended funding for Title VIII nurse education programs at fiscal year 2012 levels, a reduction of more than 4 percent from 2011. These programs now face the uncertain impact of sequestration, which could eliminate 645 training opportunities for advanced practice registered nurses. Funding for Advanced Education Nursing in fiscal year 2012 totaled only \$64 million. This is the only Federal funding source for Nurse Practitioner education programs.

Title VIII Nursing Workforce Development Programs

The Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act have provided the resources to help educate and prepare nurse practitioners and other qualified nurses to meet our Nation's healthcare needs for nearly half a century. Title VIII programs reinforce nursing education from entry-level preparation through graduate study, and support the institutions that prepare NPs and other nurses to practice in rural and medically underserved communities. These are the only Federal programs focused on filling the gaps in the workforce of health professionals unmet by traditional market forces and on producing a workforce capable of caring for the Nation's increasingly diverse population.

Title VIII programs also address the serious need for more nursing and Nurse Practitioner faculty. Nursing schools were forced to turn away nearly 80,000 qualified applications from entry-level baccalaureate and graduate nursing programs in 2012, according to an AACN 2012–2013 enrollment and graduation survey, with faculty vacancies being a primary reason. The Title VIII Nurse Faculty Loan Program aids in increasing nursing school enrollment capacity by supporting students pursuing graduate education in exchange for their service as faculty for 4 years after graduation. The NP Roundtable urges you to provide \$251 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act in fiscal year 2014.

Nurse-Managed Health Clinics

Nurse-Managed Health Clinics (NMHCs) are health care delivery sites managed by Nurse Practitioners and other APRNs, staffed by an interdisciplinary team of healthcare providers that may include physicians, social workers, public health nurses, and therapists. These clinics are often associated with a school, college, university, or department of nursing, and occasionally with community health centers or independent nonprofit healthcare agencies.

NMHCs are particularly important threads in the Nation's healthcare safety net, caring for patients in medically underserved areas including rural communities, Native American reservations, senior citizen centers, elementary schools, and urban housing developments. Treating populations that are among the most vulnerable to chronic illnesses, NMHCs are committed to the management and reduction of acute and chronic disease and creating healthier communities by providing primary care and other services, as well as counseling and educating patients and the community regarding health promotion and disease prevention. These clinics also serve as important clinical education training sites for NPs, other nursing students and health professionals. This is particularly important given the lack of clinical training sites that has been recognized as one of the barriers to nursing school enrollment. The NP Roundtable requests that you provide \$20 million for the Nurse-Managed Health Clinics authorized under Title III of the Public Health Service Act in fiscal year 2014.

The National Institute of Nursing Research

As one of the 27 Institutes and Centers at the National Institutes of Health (NIH), the National Institute of Nursing Research (NINR) funds research that provides the evidence-based foundation for nursing practice. Nurse-scientists at NINR examine ways to innovate and improve care models to deliver safe, high quality health services in more cost-effective ways. NINR engages in research on improving

the management of care for patients during illness and recovery, reducing the risks of disease and disability, promoting healthy lifestyles, enhancing the quality of life for those with chronic disease, and compassionately caring for individuals at the end of life. In addition, NINR provides critically needed faculty to support the education of the next generations of nurses and Nurse Practitioners; its training programs develop the nurse-researchers of the future, many of whom go on to serve as faculty in our Nation's nursing schools. The NP Roundtable encourages you to provide \$150 million for the NINR in fiscal year 2014.

Nurse Practitioners recognize that controlling the growth of Federal spending is a national priority, but they also know it is critical for Congress to provide sustained stable funding to maintain nurse practitioner education programs. Without a workforce of well-educated and clinically prepared NPs providing evidence-based care to those in need, our healthcare system will not be sustainable. The NP Roundtable respectfully urges you to provide for that workforce by committing \$251 million for the Title VIII Nursing Workforce Development programs, \$20 million for Nurse-Managed Health Clinics, and \$150 million for the National Institute of Nursing Research in fiscal year 2014.

American Association of Nurse Practitioners
Gerontological Advanced Practice Nurses Association
National Association of Nurse Practitioners in Women's Health
National Association of Pediatric Nurse Practitioners
National Organization of Nurse Practitioner Faculties

PREPARED STATEMENT OF THE OVARIAN CANCER NATIONAL ALLIANCE

The Ovarian Cancer National Alliance (the Alliance) appreciates the opportunity to submit comments for the record regarding the Alliance's fiscal year 2014 funding recommendations. We believe these recommendations are critical to ensure advances to help reduce and prevent suffering from ovarian cancer.

For 16 years, the Alliance has worked to increase awareness of ovarian cancer and advocate for additional Federal resources to support research that would lead to more effective diagnostics and treatments. As an umbrella organization with more than 60 national, State and local organizations, the Alliance unites the efforts of survivors, grassroots activists, women's health advocates and health care professionals to bring national attention to ovarian cancer. The Ovarian Cancer National Alliance is the foremost advocate for women with ovarian cancer in the United States. To advance the interests of women with ovarian cancer, the organization advocates at a national level for increases in research funding for the development of an early detection test, improved health care practices and life-saving treatment protocols. The Ovarian Cancer National Alliance educates health care professionals and raises public awareness of the risks, signs and symptoms of ovarian cancer.

Approximately 22,000 women are diagnosed with ovarian cancer every year, and more than 14,000 women die from the disease. Ovarian cancer is the deadliest gynecologic cancer; fewer than half of women survive 5 years from diagnosis and only one-third survive 10 years. At this point, there is no reliable test we can use to screen women or catch the disease early. There are some known risk factors, including a genetic risk of breast/ovarian cancer, hormone replacement therapy and aging. Factors that decrease the risk of developing ovarian cancer include use of oral contraceptives, breastfeeding and removal of the fallopian tubes/ovaries. The majority of women with the disease have at least one recurrence, and for many of them, treatment eventually stops working. Ovarian cancer is the fifth leading cause of cancer deaths among women in the United States. That is why research and public health programs are so important for ovarian cancer.

The National Cancer Institute and the Centers for Disease Control and Prevention both do significant and valuable work around ovarian cancer. We are grateful for the Committee's continued support of these agencies, and the programs they undertake to lower the burden of ovarian cancer.

The NCI is the single largest nonprofit funder of ovarian cancer research domestically, funding approximately 75 percent of all nonprofit ovarian cancer research done in the United States. In fiscal year 2011, the NCI spent approximately \$110 million on ovarian cancer research, including large grants to cancer centers and cooperative groups as well smaller grants for research on topics including overcoming drug resistance, angiogenesis—cutting off blood supply to tumors, and exploring the link between high density breasts and risk for ovarian cancer.

Recent highlights of NCI funded research include: a large trial of a new ovarian cancer drug, Avastin, which was shown to improve the time women's cancer stayed in remission; studies showing that prophylactic surgery for high risk women, includ-

ing the removal of just a woman's fallopian tubes, significantly reduces the odds of developing ovarian cancer; and a study showing that screening average risk women with our current tools does not reduce mortality. The results of The Cancer Genome Atlas—another study funded by NCI—showed us how important personalized medicine is for ovarian cancer. The Atlas told us that each case of ovarian cancer is genetically unique, so we are going to have our work cut out for us to identify targets and develop and test drugs.

The CDC has two programs directly related to ovarian cancer. The first raises awareness of the risks and symptoms of gynecologic cancers through advertising and educational materials. As of December 2012, PSAs about gynecologic cancer had generated 2.62 billion audience impressions and paid media generated 187 million audience impressions. Studies conducted by the CDC have shown that both women and health providers are unaware of the symptoms of ovarian cancer and current recommendations against screening. This data shows the clear need for continued education.

The second CDC program is focused on epidemiological research. Current research includes an evidence review of birth control as an intervention for those at high risk of developing ovarian cancer, a study of barriers to determine why women don't see specialists for surgery, as well as analyses of data on disparities and other patterns of survival.

While we clearly have a long way to go, we have made progress in our understanding of ovarian cancer. We have seen new treatments developed over the past twenty years, and we have a better understanding of where ovarian cancer develops and who is at risk for this deadly disease. In addition, we have a larger and stronger network of survivors and family members who can support one another.

The Alliance maintains a long-standing commitment to work with Congress, the Administration and other policy makers and stakeholders to improve the survival rate for women with ovarian cancer through education, public policy, research and communication. Please know we appreciate and understand that our Nation faces many challenges, including limited resources. We thank you for continuing to support programs that help women and health providers better understand and treat ovarian cancer. We know these programs have reduced suffering. We know women whose lives have been saved by knowing they were at high risk or who got new treatments that kept their cancer at bay. We respectfully request that you maintain support for these critical activities.

ONE VOICE AGAINST CANCER FISCAL YEAR 2014 APPROPRIATIONS REQUESTS

Program	Amount (millions)
National Institutes of Health	32,632
National Cancer Institute	5,349
National Institute on Minority Health and Health Disparities	283
Centers for Disease Control and Prevention	515
Comprehensive Cancer Control Initiative	50
Cancer Registries	65
National Breast & Cervical Cancer Early Detection Program	275
Colorectal Cancer	70
Skin Cancer	5
Prostate Cancer	25
Ovarian Cancer	10
Geraldine Ferraro Blood Cancer Program	4.67
Johanna's Law: The Gynecologic Cancer Education and Awareness Act	10
Office of Smoking and Health	197

ONE VOICE AGAINST CANCER MEMBERS

Alliance for Prostate Cancer Prevention	American Congress of Obstetricians and Gynecologists
American Academy of Dermatology Association	American Social Health Association
American Association for Cancer Research	American Society of Clinical Oncology
American Cancer Society Cancer Action Network	American Society for Radiation Oncology
American College of Surgeons	Asian & Pacific Islander American Health Forum
Commission on Cancer	Association of American Cancer Institutes

Bladder Cancer Advocacy Network	National Cervical Cancer Coalition
Cancer Support Community	National Coalition for Cancer Research (NCCR)
Charlene Miers Foundation for Cancer Research	National Coalition for Cancer Survivorship
Colon Cancer Alliance	National Patient Advocate Foundation
CureSearch for Children's Cancer	Oncology Nursing Society
Fight Colorectal Cancer	Ovarian Cancer National Alliance
Friends of Cancer Research	Pancreatic Cancer Action Network
Intercultural Cancer Council Caucus	Pennsylvania Prostate Cancer Coalition
International Myeloma Foundation	Prevent Cancer Foundation
LIVESTRONG	Preventing Colorectal Cancer
Leukemia & Lymphoma Society	Sarcoma Foundation of America
Malecare Prostate Cancer Support	Society of Gynecologic Oncology
Men's Health Network	Susan G. Komen for the Cure Advocacy Alliance
National Alliance of State Prostate Cancer Coalitions	Us TOO International Prostate Cancer Education and Support Network
National Association of Chronic Disease Directors	
National Brain Tumor Society	

PREPARED STATEMENT OF THE PARKINSON'S ACTION NETWORK

Dear Chairman Harkin and Ranking Member Moran: The Parkinson's Action Network (PAN) appreciates the opportunity to comment on the fiscal year 2014 appropriations for the U.S. Department of Health and Human Services. Our comments will focus on the importance of Federal investment in biomedical research at the National Institutes of Health (NIH) and the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. PAN supports at least \$32 billion in funding for the NIH and the President's budget request of approximately \$100 million for the BRAIN Initiative in fiscal year 2014, \$40 million of which will come from the NIH.

PAN is the unified voice of the Parkinson's community advocating for better treatments and a cure. In partnership with other Parkinson's organizations and our powerful grassroots network, we educate the public and Government leaders on better policies for research and improved quality of life for the estimated 500,000 to 1.5 million Americans living with Parkinson's, for whom there is no treatment available that slows, reverses, or prevents progression.

As the second most common neurological condition after Alzheimer's disease, Parkinson's disease is projected to grow substantially over the next few decades as the size of the elderly population grows and will have a direct impact on the health care system and economy. A recent study published in *Movement Disorders* estimated that the economic burden of Parkinson's disease is at least \$14.4 billion a year in the United States, and the prevalence of Parkinson's will more than double by the year 2040.¹ In addition, the study calculated an additional \$6.3 billion in indirect costs such as missed work or loss of a job for the patient or family member who is helping with care, long-distance travel to see a neurologist or movement disorder specialist, as well as costs for home modifications, adult day care, and personal care aides. A second study also published in *Movement Disorders* projected that if Parkinson's progression were slowed by 50 percent, there would be a 35 percent reduction in excess costs, representing a dramatic reduction in cost of care spread over a longer expected survival.² Both studies highlight the enormous economic implications of this devastating disease, and make it abundantly clear that increased research funding is a wise investment on the front end to help significantly lower or eliminate costs on the back end.

Sustained growth for the NIH should be an urgent national priority. The NIH supports research grants in all fifty States designed to identify and develop medical discoveries that improve people's health, understand disease, and save lives. More than 80 percent of its research dollars go to universities, research institutions, and small businesses, which directly create thousands of jobs and grow local economies across the country. In 2012, NIH funding supported more than 402,000 jobs and generated more than \$57.8 billion in economic activity. NIH remains the largest

¹"The Current and Projected Economic Burden of Parkinson's Disease in the United States," *Movement Disorders*, Vol. 000, No. 000, 2013.

²"An Economic Model of Parkinson's Disease: Implications for Slowing Progression in the United States," *Movement Disorders*, Vol. 00, No. 00, 2012.

funder of Parkinson's research, supporting more than \$154 million in funding for Parkinson's disease in fiscal year 2012.

Under sequestration, instead of increasing research budgets to tackle the diseases of the future, NIH has been cut by more than \$1.5 billion. While funding cuts may not be felt immediately or all at once, they will delay years of critical research on a cure for Parkinson's and other diseases. For instance, the National Institute of Neurological Disorders and Stroke (NINDS), which is the primary supporter of the Parkinson's research portfolio at NIH, will be unable to expand the NINDS Parkinson's Disease Biomarkers Program, which brings together multiple stakeholders dedicated to finding diagnostic and progression biomarkers for Parkinson's disease, as planned. A Parkinson's biomarker could hasten new treatments and improve diagnosis of the disease in the future.

By investing in biomedical research both at the Federal level and in the private sector, and creating results-driven public-private partnerships, the scientific community can develop more innovative treatments and, one day, a cure for Parkinson's. That is why PAN is supportive of the new BRAIN Initiative, which aims to revolutionize our understanding of the human brain by bringing together the NIH, the Defense Advanced Research Projects Agency, and the National Science Foundation as well as key private sector partners, like the Allen Institute for Brain Research. We are supportive of the President's request for approximately \$100 million of fiscal year 2014 funds to jumpstart this exciting new effort, with \$40 million coming from the NIH. We are hopeful that this cross-cutting and targeted effort can answer questions and create tools that will be directly applicable to the millions of people living with neurological diseases.

PAN urges the subcommittee to prioritize biomedical research funding by supporting at least \$32 billion for the NIH overall and supporting the President's request of \$40 million at the NIH for the BRAIN Initiative. We look forward to working with the subcommittee as the fiscal year 2014 appropriations process moves forward.

PREPARED STATEMENT OF THE PHYSICIAN ASSISTANT EDUCATION ASSOCIATION
(PAEA)

On behalf of the 174 accredited physician assistant (PA) education programs in the United States, the Physician Assistant Education Association (PAEA) is pleased to submit these comments on the fiscal year 2014 appropriations for PA education programs that are authorized through Title VII of the Public Health Service Act. PAEA supports funding of at least \$264.4 million in fiscal year 2014 for the health professions education programs authorized under Title VII of the Public Health Service Act and administered through the Health Resources and Services Administration (HRSA) and requests \$7.65 million in support of PA programs operating across the country. This is the only designated source of Federal funding for PA education and is crucial to the education system's ability to meet the demand for training and to continue to produce highly skilled physician assistants ready to enter the health care workforce in an average of 26 months.

Need for Increased Federal Funding

The unmet need for primary care services in the United States is well documented, and only expected to grow as Baby Boomers age and the Affordable Care Act is fully implemented. The very parameters of access and health care quality are rapidly evolving. Yet the one constant in our health care system remains the need for qualified health care providers in numbers sufficient to meet demand, and primary care has been clearly identified as the critical entry point into the health care system where that access must be guaranteed. PAs stand ready for the challenges in primary care, and could play an even larger role with appropriate financial support and through innovations in the PA education system.

Like physicians, the PA profession also faces shortages that will hinder its ability to help address the primary care issue in the United States. Without new solutions, at the current output of approximately 6500 graduates from PA programs per year, these shortages will persist, particularly in the rural and underserved communities where care is needed the most. Title VII funding is the only opportunity for PA programs to apply for Federal funding and plays a crucial role in developing and supporting the PA education system's ability to produce the next generation of these critical advanced practice clinicians.

Background on the Profession

Since the 1960s, PAs have consistently demonstrated they are effective partners in health care, readily adaptable to the needs of an ever-changing delivery system.

Physician assistants are licensed health professionals with advanced education in general medicine. PAs practice medicine as members of a team working with supervising physician. They exercise autonomy in medical decisionmaking and provide a broad range of medical and therapeutic services to diverse populations in rural and urban settings. In all 50 States, PAs carry out physician-delegated duties that are allowed by law and within the physician's scope of practice and the PA's training and experience, including prescriptive authority in all 50 States, the District of Columbia, and Guam. The combination of medical training, advanced education and hands-on experience allows PAs to practice with significant autonomy, and in rural and other medically underserved areas where they are often the only full-time medical provider. The profession is well established, yet young enough to embrace new models of care, adopt innovative approaches to training and education, and adapt to health system challenges as they arise. The PA practice model is, by design, a team-based approach to patient-centered care where the PA works in tandem with a physician and other health professionals. This PA practice approach to quality care is uniquely aligned with the patient-centered, collaborative, interprofessional and outcomes-based care models expected to transform the U.S. health care system.

PA Education: The Pipeline for Physician Assistants

There are currently 174 accredited PA education programs in the United States—a 23 percent increase over the past 5 years; together these programs graduate nearly 6,422 PA students each year. PAs are educated as generalists in medicine and their flexibility allows them to practice in more than 60 medical and surgical specialties. More than one third of PA program graduates practice in primary care.

The average PA education program is 26 months in length and typically, 1 year is devoted to classroom study and approximately 12 months is devoted to clinical rotations. Most curricula include 340 hours of basic sciences and nearly 2,000 hours of clinical medicine.

As of today, approximately 65 new PA programs are in the pipeline at various stages of development, moving toward accredited status. The growth rate in the applicant pool is even more remarkable. Since its inception in 2001 until the most recent application cycle, the Centralized Application Service (CASPA) used by most programs grew from 4,669 applicants to over 19,000. In March 2009, there were a total of 12,216 applicants to PA education programs; as of March 2013, there were 18,900 applicants to PA education programs. This represents a 54 percent increase in CASPA applicants over the past 5 years.

The PA profession is expected to continue to grow as a result of the projected shortage of physicians and other health care professionals, the growing demand for care driven by an aging population, and the continuing strong PA applicant pool. The Bureau of Labor Statistics projects a 39 percent increase in the number of PA jobs between 2008 and 2018. The way that PAs are trained in America—the caliber of our institutions and the expertise of our educators—is the gold-standard throughout the world and that must be maintained. With its relatively short initial training time and the flexibility of generalist-trained PAs, the PA profession is well-positioned to help fill projected shortages in the numbers of health care professionals—if appropriate resources are available to support the education system behind them.

AREAS OF ACUTE NEED

Faculty Shortages

Faculty development is one of the profession's critical needs and educators are an often overlooked element to developing an adequate primary care workforce. Nearly half of PA program faculty are 50 years or older and the PA teaching profession faces large numbers of retirements in the next 10–15 years. An interest in education must be developed early in the educational process to ensure a continuous stream of educators and we must alleviate the significant loan burdens that prevent many physician assistants from entering academia. In order to attract the most highly qualified individuals to teaching, PA education programs must have the resources to start that process, and train faculty in academic skills, such as curriculum development, teaching methods, and laboratory instruction. Most educators come from clinical practice and these non-clinical professional skills are essential to a successful transition from clinical practice to a classroom setting. Without Federal support, we will continue to cycle through existing faculty and face an impending shortage of teachers who are prepared for and committed to the critical teaching role in PA student education.

Clinical Site Shortages

Outside of the classroom, the PA education faces additional challenges in meeting demand. A lack of clinical sites for PA education is hampering PA programs' ability

to produce the next generation of PAs at the pace needed to meet the demand for primary care in the U.S. This shortage is caused by two main factors: a shortage of medical professionals willing to teach students as they are cycling through their clinical rotations (preceptors), and a lack of sites with the physical space to teach.

This phenomenon is experienced throughout the health professions, and is particularly acute in primary care. It has created unintentional competition for clinical sites and preceptors within and among PAs, physicians and advance practice nurses. Federal funding can help incentivize practicing clinicians to both offer their time as preceptors, and volunteer their clinical operations as training grounds for PAs and other health professionals to directly interact with patients. PAEA believes that interprofessional clinical training and practice are necessary for optimum patient care and will be a defining model of health care in the U.S. in the 21st century. We can only make that a reality if we begin to build a sufficient network of health professionals who are willing to teach the next generation of primary care professionals—that approach will benefit PAs as well as the future physicians and nurses that comprise the full primary care team.

Enhancing Diversity

Generalist training, workforce diversity, and practice in underserved areas are key priorities identified by HRSA and are consistent with those of PAEA. It is increasingly important for patient care quality that the health workforce better represents America's changing demographics, as well as addresses the issues of disparities in health care. PA programs have been committed to attracting students from underrepresented minority groups and disadvantaged backgrounds into the profession, through programs such as the National Health Service Corps (NHSC), Scholarships for Disadvantaged Students (SDS) and the Health Careers Opportunity Program (HCOP). Studies have found that health professionals from underserved areas are three to five times more likely to return to underserved areas to provide care and PA programs are looking for unique ways to recruit diverse individuals into the profession, and sustain them as leaders in the education field. If we can provide resources to schools that are particularly poised to improve their diversity recruitment efforts and replicate or create best practices, we can begin to address this systemic need.

Efforts to increase workforce diversity in the PA profession are enhanced when colleges and universities are able to leverage primary care training funds with other Federal programs that specifically target recruitment and retention of underrepresented minorities. PAEA therefore supports the restoration of funding for the Health Careers Opportunity Program (HCOP), and increased funding for the Scholarships for Disadvantaged Students and National Health Service Corps. Historically, access to higher education has been constrained for individuals from disadvantaged backgrounds. Funding for HCOP that targets the physician assistant profession and scholarship programs that provide support for students with limited financial resources helps to provide a clear path for students who might not otherwise consider a physician assistant career.

Veterans

The first physician assistant class of 1965 was comprised of Navy corpsman who served during the Vietnam War. Veterans with medical backgrounds are excellent potential candidates for PA programs and special incentives for both the schools and students can help expedite the process of matriculation into the educational system. Over the past 18 months, PAEA has been involved in initiatives to create a pathway for veterans interested in becoming physician assistants. PAEA is currently partnering with the American Academy of Physician Assistants, the National Commission on Certification of Physician Assistants, and the Accreditation Review Commission on Education for the Physician Assistant (ARC-PA) to promote the opportunities for veterans that exist in the PA profession. PAEA has also created two groups tasked with identifying best practices in PA education and ways to quantify military experiences for academic credit.

The Recruitment and Training group is working to develop and employ outreach methods to engage military personnel and veterans who are seeking careers in health care. The Vet 2 PA workgroup was formed with the goal of identifying PA programs with bridge programs instituted to help military service members more easily transition into PA training programs. In addition, there was a special priority created in the last PA Primary Care Training Grant competition for programs that provided supportive services for veterans, including academic support and mentoring services, among others. Eleven out of the 12 PA education program grantees, all members of PAEA, had a veteran-specific initiative in their training grant application.

Title VII Funding

Title VII funding fills a critical need for curriculum development, faculty development, clinical site expansion and diversification of the primary care workforce. These funds enhance clinical training and education, assist PA programs with recruiting applicants from minority and disadvantaged backgrounds, and enables innovative programs that focus on educating a culturally competent workforce. Title VII funding increases the likelihood that PA students will practice in medically underserved communities with health professional shortages. The absence of this funding would result in the loss of care to patients with the most urgent need for access to care.

Title VII support for PA programs was strengthened in 2010 when Congress enacted a 15 percent allocation in the appropriations process specifically for PA programs working to address the health provider shortage. This funding will enhance capabilities to train a growing PA workforce and is likely to increase the pool for faculty positions as a result of PA programs now being eligible for faculty loan repayment.

Here we provide several examples of how PA programs have used Title VII funds to creatively expand care to underserved areas and populations, as well as to develop a diverse PA workforce.

- One Texas program has used its PA training grant to support the program at a distant site in an underserved area. This grant provides assistance to the program for recruiting, educating, and training PA students in the largely Hispanic South Texas and mid-Texas/Mexico border areas and supports new faculty development.
- A Utah program has used its PA training grant to promote interprofessional teams—an area of strong emphasis in the Patient Protection and Affordable Care Act. The grant allowed the program to optimize its relationship with three service-learning partners, develop new partnerships with three service-learning sites, and create a model geriatric curriculum that includes didactic and clinical education.
- An Alabama program used its PA training grant to update and expand the current health behavior educational curriculum and HIV/STD training. They were also able to include PA students from other programs who were interested in rural, primary care medicine for a four-week comprehensive educational program in HIV disease diagnosis and management.

Recommendations on fiscal year 2014 Funding

The Physician Assistant Education Association requests the Appropriations Committee support funding for Title VII health professions programs at a minimum of \$264.4 million for fiscal year 2014. This level of funding is crucial to support the Nation's ability to produce and maintain highly skilled primary care practitioners, particularly those who will practice in medically underserved areas and serve vulnerable populations. Additionally, we ask for the 15 percent allocation for PA education programs in the Primary Care cluster as mandated in the Affordable Care Act. This \$7.65 million will enable the education system to produce 1,400 more primary care PAs over 5 years. We thank the members of the subcommittee for their support of the health professions and look forward to your continued commitment to finding solutions to the Nation's health workforce shortage. We appreciate the opportunity to present the Physician Assistant Education Association's fiscal year 2014 funding recommendation.

PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA/ASSOCIATION
OF POPULATION CENTERS

INTRODUCTION

Thank you, Chairman Harkin, Ranking Member Moran, and other distinguished members of the subcommittee, for this opportunity to express support for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). The Population Association of America (PAA) and Association of Population Centers (APC) are pleased to endorse funding recommendations made by the Ad Hoc Group for Medical Research Funding and Friends of National Center for Health Statistics for NIH and NCHS, respectively. Specifically, we urge the Committee to provide the NIH with \$32 billion in fiscal year 2014 and to provide the NCHS with the Administration's request, \$181.5 million. Further, we encourage the subcommittee to stop the pernicious cuts to research funding and statistical agencies that squander invaluable scientific opportunities and threaten the ability of our

members to continue making important contributions towards improving the health and well being of the American people, to train the next generation of population scientists, and to prevent the permanent loss of key longitudinal survey data.

BACKGROUND ON THE PAA/APC AND DEMOGRAPHIC RESEARCH

The Population Association of America (PAA) (www.populationassociation.org) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) (www.popcenters.org) is a similar organization comprised of over 40 universities and research groups nationwide that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD). Below are examples of the important population research activities that these Institutes support.

NATIONAL INSTITUTE ON AGING

According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase three-fold, to 19 million. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well being characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of Federal support for basic research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging, the NIA BSR Division also supports several large, accessible data surveys. These surveys include a new nationally representative study, the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying trends in late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the long-term care utilization of people with chronic disabilities. NHATS is enabling researchers to continue important research on late-life disability trends and those factors (socio-economic, demographic, health) that may influence changes in disability across different populations.

Another NIA survey, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the U.S. Since 1992, the HRS has tracked 27,000 people, providing data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. HRS is so respected that the study is being replicated currently in 30 other countries, providing important data on how the U.S. compares with other countries whose populations are aging more rapidly. In March 2012, HRS posted genetic data collected voluntarily from over half of the HRS participants to dbGAP, the NIH's online genetics database. These data are now available for analysis by qualified researchers to track the onset and progression of diseases and disabilities affecting the elderly. In the last year, HRS data were used to report a number of findings, including a significant study published in *The New England Journal of Medicine* in April 2013, which identified the costs of dementia. The study found that caring for people with dementia in the United States in 2010 costs between \$159 billion to \$215 billion, and these costs could rise dramatically with the increase in the numbers of older people in coming decades. The researchers found these costs of care comparable to, if not greater than, those for heart disease and cancer.

As members of the Friends of the NIA, PAA and APC endorse the coalition's recommendation that NIA receive \$1.4 billion in fiscal year 2014.

EUNICE KENNEDY SHRIVER NATIONAL INSTITUTE ON CHILD HEALTH AND HUMAN
DEVELOPMENT

Since its establishment in 1968, the Eunice Kennedy Shriver NICHD Center for Population Research has supported research on population processes and change. As a result of the Institute's recent reorganization, this research is now housed in the Population Dynamics Branch. This branch supports research in three broad areas: demography, HIV/AIDs, other sexually transmitted diseases, and other reproductive health; and population health, with focus on early life influences and policy.

NICHD is the major supporter of the national studies that track the health and well being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents; the National Longitudinal Study of Youth, a multigenerational study of health and development; and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. NICHD supports the prompt and widespread release of demographic data collected with NIH and other Federal Government funding through the Demographic Data Sharing and Archiving project.

One of the most important population research programs the NICHD supports is the Research Infrastructure for Demographic and Behavioral Population Science (DBPop). This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists, while at the same time providing incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating research infrastructure within and across research institutions. DBPop supports research at 24 private and public research institutions nationwide, the focal points for the demographic research field for innovative research and training and the development and dissemination of widely used large-scale databases.

NIH-funded demographic research provides critical scientific knowledge on issues of greatest consequence for American families: marriage and childbearing, childcare, work-family conflicts, and family and household behavior. Demographic research is having a large impact in public health, particularly on issues such as infant and child health and development, and adolescent and young adult health, and health disparities. Research supported by the Population Dynamics branch has revealed the critical role of marriage and stable families in ensuring that children grow up healthy, achieving developmental and educational milestones. Branch-supported researchers have published a number of recent findings, including a study, based on Add Health data, which concluded that women who are overweight or obese years during the transition from adolescence to adulthood are more likely to later deliver babies with a higher birth weight, putting the next generation at a higher risk of obesity-related health outcomes. In another published study, researchers using genetic and survey data from the Fragile Families and Child Well Being Study, found that post-partum depression was most likely among women with both at-risk genetic profiles and low educational levels.

As members of the Friends of the NICHD, PAA and APC endorse the coalition's recommendation that the Institute receive \$1.2 billion in fiscal year 2014.

NATIONAL CENTER FOR HEALTH STATISTICS

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the Nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the States to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (HIS), and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our Nation's health. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

Despite recent steady funding increases, NCHS continues to feel the effects of long-term funding shortfalls, compelling the agency to undermine, eliminate, or further postpone the collection of vital health data. For example, in 2009, sample sizes in HIS and NHANES were cut, while other surveys, most notably the National Hospital Discharge Survey, were not fielded. In 2009, NCHS proposed purchasing only "core items" of vital birth and death statistics from the States (starting in 2010),

effectively eliminating three-fourths of data routinely used to monitor maternal and infant health and contributing causes of death. Fortunately, Congress and the new Administration worked together to give NCHS adequate resources and avert implementation of these draconian measures. Also, funding from the Prevention and Public Health Fund has been an invaluable source of support for the agency since fiscal year 2011, providing much needed funding to, for example, add components to NHANES, purchase updated vital statistics data from the States, and facilitate the implementation of electronic birth records in the all States. With funding from the NIH, the agency is also working to expedite the release of mortality data from the National Death Index. However, the progress NCHS has made is threatened if the agencies that it relies on for support (through funding from the HHS evaluation tap and via interagency agreements) continue to be cut.

Thank you for considering the importance of these agencies under your jurisdiction that benefit the population sciences. Despite challenges facing the subcommittee, we urge you to support \$32 billion for NIH and \$181.5 million for NCHS in fiscal year 2014. Further, we urge you to work to reverse the impact sequestration and years of funding levels below inflation have had on the entire public health continuum, which includes NIH and NCHS.

PREPARED STATEMENT OF PREVENT BLINDNESS AMERICA
FUNDING REQUEST OVERVIEW

Prevent Blindness America appreciates the opportunity to submit written testimony for the record regarding fiscal year 2014 funding for vision and eye health related programs. As the Nation's leading non-profit, voluntary health organization dedicated to preventing blindness and preserving sight, Prevent Blindness America maintains a long-standing commitment to working with policymakers at all levels of Government, organizations and individuals in the eye care and vision loss community, and other interested stakeholders to develop, advance, and implement policies and programs that prevent blindness and preserve sight. Prevent Blindness America respectfully requests that the subcommittee provide the following allocations in fiscal year 2014 to help promote eye health and prevent eye disease and vision loss:

- Provide at least \$508,000 million to maintain vision and eye health efforts at the Centers for Disease Control and Prevention (CDC).
- Support the Maternal and Child Health Bureau's (MCHB) National Center for Children's Vision and Eye Health (Center).
- Provide at least \$640 million in fiscal year 2014 to sustain programs under the Maternal and Child Health (MCH) Block Grant.
- Provide \$730 million to the National Eye Institute (NEI) in order to bolster efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis, and advance prevention and treatment efforts.

INTRODUCTION AND OVERVIEW

Vision-related conditions affect people across the lifespan from childhood through elder years. Good vision is an integral component to health and well-being, affects virtually all activities of daily living, and impacts individuals physically, emotionally, socially, and financially. Loss of vision can have a devastating impact on individuals and their families. An estimated 80 million Americans have a potentially blinding eye disease, three million have low vision, more than one million are legally blind, and 200,000 are more severely visually blind. Vision impairment in children is a common condition that affects five to 10 percent of preschool age children. Vision disorders, including amblyopia ("lazy eye"), strabismus ("cross eye"), and refractive error are the leading cause of impaired health in childhood.

Alarming, while half of all blindness can be prevented through education, early detection, and treatment, the NEI reports that "the number of Americans with age-related eye disease and the vision impairment that results is expected to double within the next three decades."¹ Among Americans age 40 and older, the four most common eye diseases causing vision impairment and blindness are age-related macular degeneration (AMD), cataract, diabetic retinopathy, and glaucoma.² Refractive errors are the most frequent vision problem in the U.S.—an estimated 150 mil-

¹"Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America," Prevent Blindness America and the National Eye Institute, 2008.

²*Ibid.*

lion Americans use corrective eyewear to compensate for their refractive error.³ Uncorrected or under-corrected refractive error can result in significant vision impairment.⁴

To curtail the increasing incidence of vision loss in America, Prevent Blindness America advocates sustained and meaningful Federal funding for programs that help promote eye health and prevent eye disease, vision loss, and blindness; needed services and increased access to vision screening; and vision and eye disease research. In a time of significant fiscal constraints, we recognize the challenges facing the subcommittee and urge you to consider the ramifications of decreased investment in vision and eye health. Vision loss is often preventable, but without continued efforts to better understand eye diseases and conditions, and their treatment, through research, to develop the public health systems and infrastructure to disseminate and implement good science and prevention strategies, and to protect children's vision, millions of Americans face the loss of independence, loss of health, and the loss of their livelihoods, all because of the loss of their vision. We thank the subcommittee for its consideration of our specific fiscal year 2014 funding requests, which are detailed below.

VISION AND EYE HEALTH AT THE CDC: HELPING TO SAVE SIGHT AND SAVE MONEY

The CDC serves a critical national role in promoting vision and eye health. Since 2003, the CDC and Prevent Blindness America have collaborated with other partners to create a more effective public health approach to vision loss prevention and eye health promotion. The CDC works to:

- Promote eye health and prevent vision loss.
- Improve the health and lives of people living with vision loss by preventing complications, disabilities, and burden.
- Reduce vision and eye health related disparities.
- Integrate vision health with other public health strategies.

Prevent Blindness America requests at least \$508,000 million in fiscal year 2014 to maintain vision and eye health efforts of the CDC. Adequate fiscal year 2014 resources will allow the CDC to continue to address the growing public health threat of preventable chronic eye disease and vision loss among at-risk and underserved populations through increased coordination and integration of vision and eye health at State and local health departments, and through community health centers and rural services.

INVESTING IN THE VISION OF OUR NATION'S MOST VALUABLE RESOURCE—CHILDREN

While the risk of eye disease increases after the age of 40, eye and vision problems in children are of equal concern. If left untreated, they can lead to permanent and irreversible visual loss and/or cause problems socially, academically, and developmentally. Although more than 12.1 million school-age children have some form of a vision problem, only one-third of all children receive eye care services before the age of six.⁵

In 2009, the MCHB established the National Center for Children's Vision and Eye Health (the Center), a national vision health collaborative effort aimed at developing the public health infrastructure necessary to promote eye health and ensure access to a continuum of eye care for young children.

The Center has established a National Advisory Committee of experts in ophthalmology, optometry, pediatrics, public health, childcare, academia, family advocacy, and others who have a stake in the field of children's vision. Members of the National Advisory Committee provide recommendations toward national guidelines for quality improvement strategies, vision screening and developing a continuum of children's vision and eye health. In addition, they serve as advisors to the Center as it pursues its goals and objectives. With this support the Center, will continue to:

- Provide national leadership in dissemination of best practices, infrastructure development, professional education, and national vision screening guidelines that ensure a continuum of vision and eye health care for children;
- Advance State-based performance improvement systems, screening guidelines, and a mechanism for uniform data collection and reporting; and

³*Ibid*

⁴*Ibid*.

⁵"Our Vision for Children's Vision: A National Call to Action for the Advancement of Children's Vision and Eye Health, Prevent Blindness America," Prevent Blindness America, 2008.

—Provide technical assistance to States in the implementation of strategies for vision screening, establishing quality improvement measures, and improving mechanisms for surveillance.

Prevent Blindness America also requests at least \$640 million in fiscal year 2014 to sustain programs under the MCH Block Grant. The MCH Block Grant enables States to expand critical health care services to millions of pregnant women, infants and children, including those with special health care needs. In addition to direct services, the MCH Block Grant supports vital programs, preventive and systems building services needed to promote optimal health.

ADVANCE AND EXPAND VISION RESEARCH OPPORTUNITIES

Prevent Blindness America calls upon the subcommittee to provide \$730 million for the NEI to bolster its efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention and treatment efforts. Research is critical to ensure that new treatments and interventions are developed to help reduce and eliminate vision problems and potentially blinding eye diseases facing consumers across the country.

Through additional support, the NEI will be able to continue to grow its efforts to:

- Expand capacity for research, as demonstrated by the significant number of high-quality grant applications submitted in response to the American Recovery and Reinvestment Act opportunities.
- Address unmet need, especially for programs of special promise that could reap substantial downstream benefits.
- Fund research to reduce healthcare costs, increase productivity, and ensure the continued global competitiveness of the United States.

By providing additional funding for the NEI at the NIH, essential efforts to identify the underlying causes of eye disease and vision loss, improve early detection and diagnosis of eye disease and vision loss, and advance prevention, treatment efforts and health information dissemination will be bolstered.

CONCLUSION

On behalf of Prevent Blindness America, our Board of Directors, and the millions of people at risk for vision loss and eye disease, we thank you for the opportunity to submit written testimony regarding fiscal year 2014 funding for the CDC's vision and eye health efforts, the MCHB's National Center for Children's Vision and Eye Health, and the NEI. Please know that Prevent Blindness America stands ready to work with the subcommittee and other Members of Congress to advance policies that will prevent blindness and preserve sight. Please feel free to contact us at any time; we are happy to be a resource to subcommittee members and your staff. We very much appreciate the subcommittee's attention to—and consideration of—our requests.

PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION (PHA)

PHA fiscal year 2014 LHHS Appropriations Recommendations:

- Protect Federal medical research and patient care programs from devastating funding cuts through sequestration and deficit reduction activities.
- \$7 billion for HRSA, an increase of \$500 million over fiscal year 2012.
- \$7.8 billion for CDC, an increase of \$1.7 billion over fiscal year 2012, including a proportional increase for the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).
- \$32 billion for NIH, an increase of \$1.3 billion over fiscal year 2012, including proportional increases for the National Heart, Lung, and Blood Institute (NHLBI); National Center for Advancing Translational Sciences (NCATS); Office of Rare Diseases Research (ORDR); Office of the Director (OD); and other NIH Institutes and Centers to facilitate adequate growth in the PH research portfolio.

Chairman Harkin, Ranking Member Moran, and distinguished members of the subcommittee, thank you for the opportunity to submit testimony on behalf of PHA. It is my honor to represent the hundreds of thousands of Americans who are affected by the devastating disease pulmonary hypertension (PH).

PHA has served the PH community for over 20 years. In 1990, three PH patients found each other with the help of the National Organization for Rare Disorders and shortly thereafter founded PHA. At that time, the condition was largely unknown amongst the general public and within the medical community; there were fewer

than 200 diagnosed cases of the disease. Since then, PHA has grown into a nationwide network of over 20,000 members and supporters, including over 240 support groups across the country.

PHA is dedicated to improving treatment options and finding cures for PH, and supporting affected individuals through coordinated research, education, and advocacy activities. Since 1996, nine medications for the treatment of PH have been approved by the Food and Drug Administration (FDA), eight of those since 2001. These innovative treatment options represent important steps forward in the medical understanding of PH and the care of PH patients, but more needs to be done to end the suffering caused by this disease. PH remains a serious and life-altering condition.

PH is a debilitating and often fatal condition where the blood pressure in the lungs rises to dangerously high levels. In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail. Symptoms of PH include shortness of breath, fatigue, chest pain, dizziness and fainting.

PH can be idiopathic, and occur without a known cause, or be secondary to other conditions, such as HIV, scleroderma, lupus, blood clots, sickle cell, and liver disease. While PH impacts individuals of all races, genders, and ages, preliminary data from the Registry to Evaluate Early and Long Term Pulmonary Arterial Hypertension Disease Management (REVEAL Registry) suggests that women develop PH at a 4:1 ratio to men.

PH is a chronic condition that is costly in terms of quality of life and healthcare expenditures. The symptoms of PH are frequently misdiagnosed, leaving patients with the false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progressed to a late stage, which makes it difficult if not impossible to treat, even with drastic action such as a heart or lung transplant. While PH remains incurable with a poor survival rate, new treatment options are improving lives and enabling some patients to manage their condition for 20 years or longer.

I would like to extend my sincere gratitude to the subcommittee for your historic support of PH programs at HRSA, CDC, and NIH. Thanks to your leadership, the PH research portfolio at NIH has advanced and improved our understanding of the disease, and awareness of PH by the general public has led to earlier diagnosis and improved health outcomes for patients. Please continue to support PH activities moving forward.

Deficit Reduction and Sequestration

Our Nation's investment in biomedical research, particularly through NIH, is an engine that drives economic growth while improving health outcomes for patients. NIH supports a significant research portfolio in pulmonary hypertension with critical research activities conducted at academic health centers across the country. The Federal commitment to this research portfolio has been the catalyst behind major breakthroughs that have improved our scientific understanding of PH and led to better health and healthcare for PH patients.

While meaningful progress has been made, PH remains a fatal condition and researchers across the country continue to work towards the goal of finding a cure. If Federal funding for NIH is substantially reduced, the current effort to capitalize on recent advancements and improve treatment options will face a serious setback. Ongoing research projects, including those being conducted at academic health centers across the country, will stall and critical new research projects will not be initiated.

In addition, reducing support for Federal biomedical research efforts sends a powerful message to the next generation about our country's lack of commitment to this field. Many talented young people interested in biomedical research will seek other career paths. Those who become the next generation of researchers will face increased competition for their talents from foreign competitors who are investing in their biomedical research infrastructure.

Over the past 15 years, 9 therapies indicated to treat PH have been developed by industry and approved by FDA. PH is a chronic, disabling, and often fatal condition and the advent of current therapies has extended life and improved quality of life for individuals with the disease. However, the treatments are complex and come with significant side effect profiles. Moreover, current therapies do not completely restore affected individuals, which means that a life with PH can be difficult for both patients and caregivers.

More work is in progress in this area, but if healthcare programs endure significant funding cuts, PH patients may see few improvements. Funding cuts to discre-

tionary health programs have the potential to drastically limit resources at FDA, undermining the agency's efforts to facilitate expeditious treatment development and potentially impair current oversight activities. Further, any cuts to the Centers for Medicare and Medicaid Services (CMS) have the potential to jeopardize access to care for PH patients by creating cost-driven barriers to available therapies.

As you work with your colleagues in Congress on deficit, budget, and appropriations issues please support the PH community by actively pursuing meaningful funding increases for critical medical research and healthcare programs.

Health Resources and Services Administration

PHA asks that you support HRSA by providing the agency with a meaningful funding increase of \$500 million in fiscal year 2014. Such a funding increase would allow the agency to initiate important new activities such as partnering with the PH experts to improve the criteria for determining lung and heart-lung transplantation for PH patients. We ask for your leadership in encouraging HRSA, specifically the United Network for Organ Sharing, to engage in active and meaningful dialogue with medical experts at the REVEAL Registry. Such a dialogue has the potential to improve the methodology used to determine lung transplantation eligibility for PH patients and to improve survivability and health outcomes following a transplantation procedure.

Centers for Disease Control and Prevention

PHA joins other voluntary health groups in requesting that you support CDC by providing the agency with an appropriation of \$7.8 billion in fiscal year 2014. Such a funding increase would allow CDC to undertake critical PH education and awareness activities, which would promote early detection and appropriate intervention for PH patients.

We are grateful to the subcommittee for providing past support of PHA's Pulmonary Hypertension Awareness Campaign. We know for a fact that Americans are dying due to a lack of awareness of PH and a lack of understanding about the many new treatment options. This unfortunate reality is particularly true among minority and underserved populations and citizens in rural areas remote from medical centers with PH expertise. More needs to be done to educate both the general public and healthcare providers if we are to save lives.

To that end, PHA has utilized the funding provided through the CDC to 1) launch a successful media outreach campaign focusing on both print and online outlets 2) expand our support programs for previously underserved patient populations and 3) establish PHA Online University, an interactive curriculum-based website for medical professionals that targets pulmonary hypertension experts, primary care physicians, specialists in pulmonology/cardiology/rheumatology, and allied health professionals. The site is continually updated with information on early diagnosis and appropriate treatment of pulmonary hypertension. It serves as a center point for discussion among PH-treating medical professionals and offers Continuing Medical Education and CEU credits through a series of online classes.

Early diagnosis of PH and timely intervention with innovative therapies can significantly improve health outcomes for PH patients. In some instances, early intervention can mitigate the need for more drastic treatment and costly treatment options, like heart-lung transplantation. In order to promote early recognition and accurate diagnosis, PHA asks the subcommittee to provide CDC with additional funding in fiscal year 2014 so that important PH education and awareness activities can be initiated through NCCDPHP.

National Institutes of Health

PHA joins the public health community in requesting that you support NIH by providing the agency with an appropriation of \$32 billion in fiscal year 2014. This modest funding increase would ensure that biomedical research inflation does not result in a loss of purchasing power at NIH, critical new initiatives like the Cures Acceleration Network (CAN) are adequately supported, and the PH research portfolio can continue to progress.

Less than two decades ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease. Thanks to advancements made through the public and private sector, patients today are living longer and better lives with a choice of nine FDA approved medications. Sustained investment in basic, translational, and clinical research can ensure that we capitalize on recent advancement and emerging opportunities to speed the discovery of improved treatment options and cures.

Expanding clinical research remains a top priority for patients, caregivers, and PH investigators. We are particularly interested in establishing a pulmonary hypertension research network. Such a network would link leading researchers around

the United States, providing them with access to a wider pool of shared patient data. In addition, the network would provide researchers with the opportunities to collaborate on studies and to strengthen the connections between basic and clinical science in the field of pulmonary hypertension research. Such a network is in the tradition of the NHLBI, which, to its credit and to the benefit of the American public, has supported numerous similar networks including the Acute Respiratory Distress Syndrome Network and the Idiopathic Pulmonary Fibrosis Clinical Research Network. We ask that you provide NHLBI with sufficient resources and encouragement to move forward with the establishment of a PH network in fiscal year 2014.

We applaud the recent establishment of NCATS at NIH. Housing translational research activities at a single Center at NIH will allow these programs to achieve new levels of success. Initiatives like CAN are critical to overhauling the translational research process and ensuring that more breakthroughs in basic research are developed into meaningful diagnostic tools and treatment options that directly benefit patients. In addition, new efforts like taking the lead on drug repurposing hold the potential to speed new treatment to patients, particularly patients who struggle with rare or neglected diseases. We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2014.

Thank you for your time and your consideration of our requests. Please contact me if you have any questions or if you require any additional information.

PREPARED STATEMENT OF THE RESEARCH WORKING GROUP OF THE FEDERAL AIDS
POLICY PARTNERSHIP—APRIL 2013

Chairman Harkin, Ranking Member Moran, and Members of the Committee, thank you for the opportunity to provide testimony on the National Institutes of Health (NIH) budget overall and for AIDS research in fiscal year 2014 (fiscal year 2014). Tomorrow's scientific and medical breakthroughs depend on your vision, leadership, and commitment to robust NIH funding this year. To this end, the Research Working Group (RWG) urges this Committee to support—at minimum—a funding target of \$35.98 billion in fiscal year 2014 to maintain the United States' position as the world leader in medical research and innovation.

Investments in health research via the NIH have paid enormous dividends in the health and wellbeing of people in the U.S. and around the world. NIH-funded HIV and AIDS research has supported innovative basic science for better drug therapies, evidence-based behavioral and biomedical prevention interventions, and vaccines that have saved and improved the lives of millions, and holds great promise for significantly reducing HIV infection rates and providing more effective treatments for those living with HIV/AIDS in the coming decade.

Despite these advances, the number of new HIV/AIDS cases continues to rise in various populations in the U.S. and around the world. There are over one million HIV-infected people in the U.S., the highest number in the epidemic's 31-year history; additionally over 50,000 Americans become newly infected every year. The evolving HIV epidemic in the U.S. disproportionately affects the poor, sexual and racial minorities, and the most disenfranchised and stigmatized members of our communities. However, with proper funding coupled with the promotion of evidence-based policies, we can capitalize on the ongoing scientific progress in prevention science, vaccines, and finding a cure for HIV, as well as addressing the comorbid illnesses such as viral hepatitis and tuberculosis that affect patients with HIV.

Major advances over the last few years in HIV prevention technologies—in particular with microbicides, HIV vaccines, circumcision, antiretroviral treatment as prevention, and pre-exposure prophylaxis (PrEP) using antiretrovirals—demonstrate that adequately resourced NIH programs can transform our lives. Federal support for AIDS research has also led to new treatments for other diseases, including cancer, heart disease, Alzheimer's, hepatitis, osteoporosis, and a wide range of autoimmune disorders. Over the years, the NIH has sponsored the evaluation of a host of vaccine candidates, some of which are advancing to efficacy trials. The successful iPrEx and HPTN 052 trials have shown the potential of antiretroviral drugs to prevent HIV infection. Moreover, increased funding will support the future testing of new microbicides and therapeutics in the pipeline via the implementation of a newly restructured, cross-cutting HIV clinical trials network that translates NIH-funded scientific innovation into critical quality-of-life gains for those most affected with HIV.

It is also essential to note that NIH-funded HIV pathogenesis and clinical research has contributed substantially to our understanding of potential curative approaches. These include, but are not limited to, therapeutic vaccines and other immune-system modulators, gene therapies, and drugs that can purge HIV from its

various reservoirs in the body. These candidates, many of which are now being further explored in human studies, are the culmination of nearly three decades of steadfast public support for basic science and pilot-phase research—support that must continue if we are to end the epidemic once and for all.

Increased funding for the NIH in fiscal year 2014 makes good bipartisan economic sense, especially in shaky times. Robust funding for the NIH overall will enable research universities to pursue scientific opportunity, advance public health, and create jobs and economic growth. In every State across the country, the NIH supports research at hospitals, universities, private enterprises, and medical schools. This includes the creation of jobs that will be essential to future discovery. Sustained investment is also essential to train the next generation of scientists and prepare them to make tomorrow's HIV discoveries. NIH funding puts 350,000 scientists to work at research institutions across the country. According to the NIH, each of its research grants creates or sustains six to eight jobs, and NIH-supported research grants and technology transfers have resulted in the creation of thousands of new, independent private-sector companies. Strong, sustained NIH funding is a critical national priority that will foster better health and economic revitalization.

Since 2003, funding for the NIH has failed to keep up with our existing research needs—damaging the success rate of approved grants and leaving very little money to fund promising new research. The real value of the increases prior to 2003 has been precipitously reduced because of the relatively higher inflation rate for the cost of research and development activities undertaken by the NIH. According to the Biomedical Research and Development Price Index, which calculates how much the NIH budget must change each year to maintain purchasing power, between fiscal year 2003 and fiscal year 2011, the cost of NIH activities increased by 32.8 percent. By comparison, the overall NIH budget increased by \$3.6 billion, or 13.4 percent, over fiscal year 2003. So in real terms, the NIH has already sustained budget decreases of close to 20 percent over the past decade due to inflation alone. As such, any further cuts to NIH on top of sequestration will have the clear and devastating effects of undermining our Nation's leadership in health research and our scientists' ability to take advantage of the expanding opportunities to advance health care. The race to find better treatments and a cure for cancer, heart disease, AIDS, and other diseases, and for controlling global epidemics like AIDS, tuberculosis, and malaria, all depend on a robust long-term investment strategy for health research at NIH.

In conclusion, the RWG calls on Congress to continue the bipartisan Federal commitment towards combating HIV as well as other chronic and life-threatening illnesses by increasing funding for the NIH to \$35.98 billion in fiscal year 2014, including funds for transfer to the Global Fund for HIV/AIDS, Tuberculosis and Malaria. A meaningful commitment to stemming the epidemic and securing the well being of people with HIV cannot be met without prioritizing the research investment at the NIH that will lead to tomorrow's lifesaving vaccines, treatments, and cures. Thank you for the opportunity to provide these written comments.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Harkin, members of the subcommittee, Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U. S. Centers for Disease Control and Prevention (CDC). The Global Polio Eradication Initiative (GPEI) is an unprecedented model of cooperation among national Governments, civil society and UN agencies working together to reach the most vulnerable children through a safe, cost-effective public health intervention of polio immunization, one which is increasingly being combined with opportunistic, complementary interventions such as the distribution of life-saving vitamin A drops. For fiscal year 2014 Rotary International is seeking \$146.3 million for the polio eradication efforts of the CDC to support full implementation of the polio eradication strategies and innovations outlined in the new Polio Eradication and Endgame Strategic Plan (2013–2018).

Progress in the Global Program to Eradicate Polio

Significant strides were made toward polio eradication in 2012 thanks to this committee's leadership in appropriating funds for the polio eradication activities of the CDC.

- India has not had a case of polio for more than 2 years.
- Eradication efforts have led to more than a 99 percent decrease in cases since the launch of the GPEI in 1988. In 2012 there were fewer cases in fewer places than at any point in recorded history with only 223 cases of polio—a 65 percent decrease compared to 2011. All but six of these cases were in the three remain-

ing polio endemic countries of Afghanistan, Pakistan, and Nigeria. Countries will remain at risk for outbreaks until polio has been eradicated in the remaining places where it persists.

- As of 1 May 2013, only 24 cases of polio have been reported in 2013 (50 percent the level of 2012).
- Incidence of type 3 polio is at historically low levels. Pakistan has not reported a case of type 3 polio for 1 year and Nigeria is now the only country with type 3 poliovirus circulation.
- Angola and the Democratic Republic of Congo, two of four countries considered to have reestablished transmission of polio, reported no cases of polio in 2012.
- Chad, another of the reestablished transmission countries has not reported a case of polio since June of 2012.

A new Polio Eradication and Endgame Strategic Plan (2013–2018) lays out the strategies for the certification of the eradication of wild poliovirus by 2018 at a total global cost of U.S. \$5.5 billion. This new plan builds on the lessons learned from the successful eradication of polio to date and the substantial advances in technology in 2012. The timely availability of funds remains essential to the achievement of a polio free world. The United States has been the leading public sector donor to the Global Polio Eradication Initiative. Members of U.S. Rotary clubs appreciate the United States' generous support. However, this support has declined as a proportion of the GPEI expenditures from approximately 19 percent just 5 years ago to 13 percent in 2012. A resumption of funding to the earlier 19 percent level would ensure vital funding for the GPEI and send a strong signal of continued leadership and commitment by the United States as the new strategic plan is implemented. Notably, funding provided by the polio affected countries themselves and by private sector donors—led by Rotary International and the Bill & Melinda Gates Foundation, has increased in recent years. The ongoing support of donor countries, like the United States, is essential to assure the necessary human and financial resources are made available to polio-endemic and at risk countries to take advantage of the window of opportunity to forever rid the world of polio. Continued leadership of the United States is essential to capitalize on past progress and certify the world polio free by the end of 2018.

The Role of Rotary International

Rotary International, a global association of more than 34,000 Rotary clubs in more than 170 countries with a membership of over 1.2 million business and professional leaders (more than 345,000 of which are in the U.S.), has been committed to battling polio since 1985. Rotary International has contributed more than U.S. \$1.2 billion toward a polio free world—representing the largest contribution by an international service organization to a public health initiative ever. Rotary also leads the United States Coalition for the Eradication of Polio, a group of committed child advocates that includes the March of Dimes Foundation, the American Academy of Pediatrics, the Task Force for Global Health, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in thanking you for your support of the GPEI.

The Role of the U.S. Centers For Disease Control and Prevention

Rotary commends CDC for its leadership in the global polio eradication effort, and greatly appreciates the subcommittee's support of CDC's polio eradication activities. The United States is the leader among donor nations in the drive to eradicate this crippling disease. Congressional support, in fiscal year 2012 and fiscal year 2013 enabled CDC to:

- continue engagement of the Emergency Operations Center (EOC) to harness agency-wide technical expertise to implement the agency's polio response in a rapid and efficient manner;
- develop a “dash board” monitoring system to collect, analyze, and visualize key indicators of campaign performance in real time to identify and address issues in advance to ensure high quality campaigns. This system, modeled on lessons from India and Pakistan, was piloted in Nigeria in July 2012 in 11 States and then fully implemented during the October campaigns.
- implement a nomad strategy in Nigeria which identified more than 560,000 children under 5 years old through census taking activities; reached more than 22,000 settlements with polio vaccine; and identified more than 4,000 settlements never visited by a vaccination team.
- provide the trained and experienced human resources to strengthen detection of polioviruses through the Stop Transmission of Polio (STOP) volunteer consultants. Since the December 2, 2011 EOC activation, the STOP program has deployed more than 500 individuals in 33 countries. CDC also developed the

National STOP program (NSTOP) to build local capacity by recruiting highly trained public health professionals to work at the State and local levels to support polio eradication. In Nigeria, NSTOP is an innovative strategy that has deployed 70 staff across northern polio affected States.

- purchase 195 million doses of oral polio vaccine for use in polio campaigns in 2012;
- conduct AFP surveillance reviews, and support WHO Expanded Program on Immunization (EPI) reviews; and
- provide technical and programmatic assistance to the global polio laboratory network through the Polio Laboratory in CDC's Division of Viral Diseases. CDC's labs provide critical diagnostic services and genomic sequencing of polioviruses to help guide disease control efforts. CDC will continue to serve as the global reference laboratory, while expanding environmental surveillance in countries to serve as a "safety measure" to detect any polioviruses circulating in areas without cases.

Continued funding will allow CDC to fully capitalize on the resources of the Emergency Operation Center to provide direct support and build capacity to continue intense supplementary immunization activities in the remaining polio-affected countries, continue leadership on data management to drive evidence-based decisionmaking, and continue to implement strategies to increase effective management and accountability. These funds will also help maintain essential certification standard surveillance.

Benefits of Polio Eradication

Since 1988, over 10 million people who would otherwise have been paralyzed are walking because they have been immunized against polio. Tens of thousands of public health workers have been trained to manage massive immunization programs and investigate cases of acute flaccid paralysis. Cold chain, transport and communications systems for immunization have been strengthened. The global network of 145 laboratories and trained personnel established by the GPEI also tracks measles, rubella, yellow fever, meningitis, and other deadly infectious diseases and will do so long after polio is eradicated.

A study published in the November 2010 issue of the journal *Vaccine* estimates that the GPEI could provide net benefits of at least \$40–50 billion. Polio eradication is a cost-effective public health investment with permanent benefits. On the other hand, as many as 200,000 children could be paralyzed in the next 10 years if the world fails to capitalize on the more than \$9 billion already invested in eradication. Success will ensure that the significant investment made by the U.S., Rotary International, and many other countries and entities, is protected in perpetuity.

ROTARY INTERNATIONAL AND THE ROTARY FOUNDATION PUBLIC DISCLOSURE OF FEDERAL GRANT FUNDS RECEIVED FROM OCTOBER 2008 TO JANUARY 31, 2013

[Funds reported in the fiscal year they were received, in thousands of U.S. dollars]

Organization	Agency/Subcontract Agreement	Program	Contract Term, Value, Period	Fiscal Year (July-June)	Funding Received
Rotary International	Open World Leadership Center.	Open World Program.	Annual, budget submitted and approved annually.	¹ Fiscal year 2009 Fiscal year 2010 ... Fiscal year 2011 ... Fiscal year 2012 ... ² Fiscal year 2013	160 240 231 289 20
Total	940
Rotary International	U.S. Agency for International Development. (Cost Reimbursable Subagreement with FHI Development 360 LLC).	Supportive Environments for Health (WASHPlus).	45 months commencing May 2011; Award ceiling \$667,292; contract ending January 2015.	Fiscal Year 2011 ... Fiscal Year 2012 ... ² Fiscal Year 2013	— 123 95
Total	218

ROTARY INTERNATIONAL AND THE ROTARY FOUNDATION PUBLIC DISCLOSURE OF FEDERAL GRANT
FUNDS RECEIVED FROM OCTOBER 2008 TO JANUARY 31, 2013—Continued
[Funds reported in the fiscal year they were received, in thousands of U.S. dollars]

Organization	Agency/Subcontract Agreement	Program	Contract Term, Value, Period	Fiscal Year (July-June)	Funding Received
Rotary International	U.S. Agency for International Development. (Task Order Subcontract agreement with CDM International Inc).	Environmental Health Indefinite Quantity Contract. (EH IQC). CLIN 3 Water Sanitation and Hygiene Technical Assistance (WASHTA).	18 months commencing May 2008, \$215,000; contract completed in November 2010.	¹ Fiscal Year 2009 Fiscal Year 2010 ... Fiscal Year 2011 ...	59 102 54
Total	215
Rotary International	U.S. Agency for International Development.	World Peace Fellow Pilot Internship Program.	One year commencing September 2008, \$50,000; contract completed in September 2009.	¹ Fiscal Year 2009 Fiscal Year 2010 ...	25 25
Total	50
Total funding by Fiscal Year for Rotary International and The Rotary Foundation:				¹ Fiscal Year 2009 Fiscal Year 2010 ... Fiscal Year 2011 ... Fiscal Year 2012 ... ² Fiscal Year 2013	244 367 285 412 115
					1,423

¹ Fiscal Year 2009 figures starting October 1, 2008.

² Fiscal Year 2013 figures as of January 31, 2013.

PREPARED STATEMENT OF THE RYAN WHITE MEDICAL PROVIDERS COALITION

Introduction

My name is James L. Raper, DSN, CRNP, JD, FAANP, FAAN; Director, 1917 HIV/AIDS Outpatient Clinic at the University of Alabama at Birmingham; and Immediate Past Co-Chair of the Ryan White Medical Providers Coalition. I respectfully submit testimony on behalf of the 1917 HIV/AIDS Outpatient Clinic at the University of Alabama at Birmingham and the Ryan White Medical Providers Coalition, which I co-chaired from 2010–2013. Thank you for the opportunity to describe the lifesaving HIV/AIDS care and treatment provided by Ryan White Part C funded programs, including my own clinic.

The 1917 Clinic is a dedicated, not-for profit outpatient HIV/AIDS medical and dental clinic established in 1988 at the University of Alabama at Birmingham. Ryan White Part C funding provides critical assistance in helping the clinic meet the needs of our patients. Today, 35 percent of the 1917 Clinic's patients are uninsured and would be at risk for losing access to lifesaving services without Ryan White Program funding.

The 1917 Clinic provides comprehensive outpatient HIV primary care services to residents of Jefferson, Walker, Winston, Cullman, Blount, St. Clair, and Shelby counties. Although our service area technically includes only these seven counties, we serve people with HIV/AIDS throughout Alabama and its neighboring States. In February 2013, the 1917 Clinic absorbed 800+ new patients from the previously Ryan White Part C funded Cooper Green Hospital's St. Georges' Clinic, which closed on January 31, 2013. The 1917 Clinic is now providing care to 30 percent of all known adults living with HIV/AIDS in Alabama.

The clinic offers the range of primary care and social services critical to successful HIV treatment, including primary medical and oral health care; on-site case management; mental health and substance abuse treatment services; onsite access to clinical trials; adherence, spiritual, risk reduction, and nutrition counseling; infusion therapy, coordination of hospital discharge planning, and home health care/hospice referral. To avoid emergency room visits, the 1917 Clinic provides 'sick call' services five days a week. Subspecialty care is available at the University's Kirklin Clinic—which is located just two blocks from the 1917 Clinic.

In addition to critical funding that Ryan White Part C provides through direct Federal grants for comprehensive medical care programs like the 1917 Clinic, most Ryan White Part C clinics (including the 1917 Clinic) also receive support from other parts of the Ryan White Program. Those funds help provide access to medication, additional medical care, dental services; and key support services, such as case management and transportation, all of which are essential components of highly effective Ryan White HIV care that results in excellent outcomes for our patients.

Adequate funding of the Ryan White Program is essential to providing both effective and efficient care for individuals living with HIV/AIDS, and I thank the subcommittee for its support of the Ryan White Part C Program. And while I am grateful for this support, and understand that times are tough, I request \$236.6 million for Ryan White Part C programs in fiscal year 2014. While I know that this is a lot of funding, it is in fact well below the estimated need. Ryan White medical providers will spend these dollars effectively and efficiently caring for patients and achieving excellent health and cost outcomes.

Ryan White Part C Programs Support Comprehensive, Expert and Effective HIV Care

Part C of the Ryan White Program funds comprehensive, expert and effective HIV care and treatment—services that are directly responsible for the dramatic decrease in AIDS-related mortality and morbidity over the last decade. The Ryan White Program supported the development of expert HIV care and treatment programs that have become patient-centered medical homes for individuals living with this serious, chronic condition. In 2011, a ground-breaking clinical trial—named the “scientific breakthrough of the year” by Science magazine—found that HIV treatment not only saves the lives of people with HIV, but also reduces HIV transmission by more than 96%—proving that HIV treatment is also HIV prevention.

The comprehensive, expert HIV care model that is supported by the Ryan White Program has been highly successful at achieving positive clinical outcomes with a complex patient population.¹ In a convenience sample of eight Ryan White-funded Part C programs ranging from the rural South to the Bronx, retention in care rates ranged from 87 to 97 percent. In estimates from the Centers for Disease Control and Prevention (CDC)—only 37 percent of all people with HIV are in regular care nationally.² Once in care, patients served at Ryan White-funded clinics do well—with 75 to 90 percent having undetectable levels of the virus in their blood. This is much higher than the estimate from the CDC that just 25 percent of all people living with HIV in the U.S. are virally suppressed.

Investing in Ryan White Part C Programs Saves Both Lives and Money

Early and reliable access to HIV care and treatment both helps patients with HIV live relatively healthy and productive lives and is more cost effective. One study from the 1917 Clinic found that patients treated at the later stages of HIV disease required 2.6 times more health care dollars than those receiving earlier treatment meeting Federal HIV treatment guidelines. On average it costs \$3,501 per person per year to provide the comprehensive outpatient care and treatment available at Part C funded programs. The comprehensive services provided often include lab work, STI/TB/Hepatitis screening, ob/gyn care, dental care, mental health and substance abuse treatment, and case management.

Current Challenges—Future Promise

However, this effective and comprehensive HIV care model is not completely supported by Medicaid or most private insurance. While many Ryan White Program clients have some form of insurance coverage, without the Ryan White Program, they would risk falling out of care. Barriers include poor reimbursement rates; benefits designed for healthier populations that fail to cover critical services, such as care coordination; and inadequate coverage for other important services, such as ex-

¹See *Improvement in the Health of HIV-Infected Persons in Care: Reducing Disparities* at <http://cid.oxfordjournals.org/content/early/2012/08/24/cid.cis654.full.pdf+html>.

²See CDC's *HIV in the United States: The Stages of Care* <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.

tended medical visits, mental health and substance use treatment. Full implementation of the Patient Protection and Affordable Care Act plus continuation of the Ryan White Program will dramatically improve health access and outcomes for many more people living with HIV disease.

Ryan White Programs Are Struggling to Meet Demand

Additionally, as a result of funding cuts and shortfalls, as well as increased patient demand, a 2012 Ryan White Medical Providers Coalition (RWMPC) survey of over 100 Ryan White Part C providers nationwide demonstrated that approximately half of the programs surveyed had to make cuts or other program changes. More specifically:

- 54 percent reported that they reduced or cut services, including 27 percent that reduced or cut support for medications, and 19 percent that reduced coverage for laboratory monitoring;
- 40 percent report longer wait times for new and/or existing patient appointments;
- 31 percent laid off staff and 30 percent froze hiring.
- 8 percent closed their clinics to new patients.

Upon the implementation of sequestration and other funding cuts, Ryan White Part C clinics indicated in the RWMPC survey that they would need to make additional reductions, including:

- 66 percent of clinics further cutting or reducing services;
- 57 percent further cutting staff; and
- 13 percent closing their clinics to new patients.

Fully Funding and Maintaining Ryan White Part C Programs Is Essential

Because of both the inadequacy of insurance coverage for people with complex conditions like HIV and the fact that some individuals will remain uncovered, even after Patient Protection & Affordable Care Act implementation, fully funding and maintaining the Ryan White Program is essential to providing comprehensive, expert and effective HIV care nationwide.

While RWMPC understands the difficulty of the current economic climate, reducing funding for HIV care and treatment is not cost-effective, will hamper the ability of Ryan White Part C programs to achieve the best possible patient outcomes and may fail to prevent new infections thereby jeopardizing our Nation's ability to capitalize on recent scientific breakthroughs that could move us toward an AIDS-free generation. Without ready access to comprehensive, expert, and effective HIV care and treatment, patients will use expensive emergency care more, and receive less effective treatment at later stages of HIV disease. Restricted access to effective HIV care and treatment also will result in reduced rates of retention in care, resulting in increased patient viral loads and increased numbers of HIV infections. And most importantly, there will be those who will lose their lives because they are not able to access these lifesaving services.

Conclusion

These are challenging economic times. While we recognize the significant fiscal constraints Congress faces in allocating limited Federal dollars, the significant financial and patient pressures that we face in our clinics throughout the United States propel us to make the fiscal year 2014 request of \$236.6 million for Ryan White Part C programs. This funding would help to support medical providers nationwide in delivering life-saving, effective HIV/AIDS care and treatment to their patients, and save millions in wasted health care dollars treating patients too late or in inappropriate, higher cost settings.

Thank you so much for your time and consideration of this request. If you have any questions, please do not hesitate to contact me at jimrape@uab.edu or the Ryan White Medical Providers Coalition Convener, Jenny Collier, at jennycollierjd@yahoo.com.

PREPARED STATEMENT OF THE SAFE STATES ALLIANCE

The Safe States Alliance, the national membership association representing public health injury and violence prevention professionals, appreciates the opportunity to provide testimony in support of the Centers for Disease Control and Prevention (CDC). Safe States Alliance supports the President's request to increase funding for the CDC's National Center for Injury Prevention and Control (Injury Center) including \$20 million for the National Violent Death Reporting System (NVDRS), \$10 million for firearm violence prevention research, and \$5 million to evaluate the Rape Prevention and Education Program. Additionally, Safe States requests an additional

\$13 million to support the Core Violence and Injury Prevention Program (VIPP), as well as restoration of CDC's Preventive Health and Health Services Block Grant (Prevent Block Grant) to \$100 million.

In 1985, the Institutes of Medicine (IOM) first called attention to the lack of recognition and funding for injury and violence prevention (IVP) as a public health issue in the United States.¹ Although some progress has been made in subsequent years, injuries and violence continue to have a significant impact on the health of Americans and the healthcare system, as injuries remain the leading cause of death for Americans ages one to 44.² As a result of injuries and violence, more than 29 million people are treated in emergency departments each year, two million are hospitalized, and approximately 180,000 people die—one person every three minutes. Every 45 minutes, one of those preventable deaths is a child.² In a single year, injuries and violence will ultimately cost \$406 billion in medical costs and lost productivity.³ In 2009, CDC estimates that injuries accounted for nearly half of all deaths among Americans from age one to 44. This is more than deaths from non-communicable diseases and infectious diseases combined.⁴

At the Federal level, the CDC Injury Center serves as the focal point for the public health approach to injury and violence prevention. Despite the enormous toll of injuries and violence and the existence of cost-effective interventions, there is no dedicated and ongoing Federal, State, or local funding to adequately respond to these problems. The CDC Injury Center only receives 2 percent of the CDC/Agency for Toxic Substances and Disease Registry (ATSDR) budget to address the significant burden of injuries and violence nationwide. In fiscal year 2012, the total Injury Center budget was only \$137.7 million, down from \$147.8 million in fiscal year 2010. The 5.1 percent cut imposed by sequestration further reduces the Injury Center's funding by an additional \$7 million. The net impact is a 12 percent cut to the Injury Center since fiscal year 2010 and a funding level below fiscal year 2000 levels.

Given its limited budget, the CDC Injury Center currently provides capacity building grants to only 20 State health departments (SHDs) through the Core Violence and Injury Prevention Program (VIPP). Core VIPP is comprised of multiple components including: Basic Prevention (20 States); Regional Network Leaders (five States); Surveillance Quality Improvement (four States); Older Adult Falls Prevention (three States); and Motor Vehicle/Child Injury Prevention (four States). With an additional investment of just \$13 million, the CDC Injury Center would be able to support injury and violence prevention programs in all States and territories, much as it does for other key public health issues, such as infectious and chronic diseases.

The National Violent Death Reporting System (NVDRS) is a State-based surveillance system that uses information from a variety of States and local agencies and sources—medical examiners, coroners, police, crime labs and death certificates—to form a more complete picture of the circumstances that surround violent deaths. As a result, NVDRS has enabled States to plan and implement more effective violence prevention programs informed by evidence and NVDRS data. The CDC Injury Center currently funds 18 States to implement NVDRS. Safe States Alliance supports the President's proposal⁵ to invest an additional \$20 million to expand NVDRS to all States.

For more than 30 years, the Prevent Block Grant has remained an essential source of Federal support, providing States with the autonomy to address their own unique health priorities and needs. In fiscal year 2011, more than 20 percent of the Prevent Block Grant was used by States to support injury and violence prevention efforts and emergency medical services. According to a recent survey conducted by Safe States Alliance, 29 States reported receiving an average of \$329,000 from the

¹National Research Council. *Injury in America: A Continuing Public Health Problem*. Washington, DC: The National Academies Press, 1985.

²Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>.

³Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Web-based Injury Statistics Query and Reporting System (WISQARS) [online] (2007) [accessed 2013 Feb 15]. Available from URL: <http://www.cdc.gov/injury/wisqars>.

⁴Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. [online] [accessed 2013 Feb 15]. Available from URL: http://www.cdc.gov/injury/overview/leading_cod.html.

⁵NOW IS THE TIME: The President's plan to protect our children and our communities by reducing gun violence. Washington, DC: White House; 2013.

Prevent Block Grant for injury and violence prevention efforts.⁶ The Prevent Block Grant is a critical source of funding for SHD injury and violence prevention programs, representing 9.4 percent of total funding in 2011. The Prevent Block Grant was used to support two of the five top injury areas addressed by State health departments in 2011—fall injury and poisonings, including prescription drug overdoses. Safe States Alliance supports restoration of the Prevent Block Grant at the \$100 million level.

The Safe States Alliance believes that all SHDs must have a comprehensive injury and violence surveillance and prevention program, similar to other public health programs for chronic disease and infectious disease prevention. SHDs provide significant leadership to reduce injuries and injury-related health care costs by: informing the development of public policies through data and evaluation; designing, implementing, and evaluating injury and violence prevention programs in cooperation with other agencies and organizations; collaborating with partners in health care and throughout the State; collecting and analyzing injury and violence data to identify high-risk groups; disseminating effective practices; and providing technical support and training to injury prevention partners and local-level public health professionals. The following are examples of how SHDs have utilized the Core VIPP, NVDRS, and Prevent Block Grant to prevent injuries and protected the lives of Americans:

- An estimated 3,143 lives have been saved since 1998 as a result of CDC-funded smoke alarm installation and fire safety education programs in high-risk communities. In funded States, more than 487,800 smoke alarms have been installed in approximately 250,000 homes. High-risk homes that were targeted by the program included children ages five and younger and adults ages 65 and older.
- NVDRS data helped Oregon to develop suicide prevention programs for high-risk groups of older adults. Almost 50 percent of men and 60 percent of women ages 65 years or older who died by suicide were reported to have a depressed mood before death. However, only a small proportion were receiving treatment for their depression before they died. These findings suggest that screening and treatment for depression may have saved lives. In response to these findings, Oregon developed and is implementing a State Older Adult Suicide Prevention Plan to improve primary care integration with mental health services so suicidal behavior and ideation is diagnosed and older adults receive appropriate treatment.
- In response to the growing epidemic of prescription drug overdoses in Ohio, the Ohio Core VIPP and the Ohio Injury Prevention Partnership developed a multidisciplinary Prescription Drug Abuse Action Group (PDAAG). Together, the group developed consensus-based recommendations for policymakers. In May 2011, the Ohio legislature passed a law containing many of the PDAAG policy recommendations including: licensure of pain management clinics; in-office dispensing limits; a Medicaid lock-in program; and Prescription Drug Monitoring Program changes.
- The Massachusetts Department of Public Health Injury and Violence Prevention Program (MDPH IVPP) worked in collaboration with partners to provide support and technical assistance to schools across the State to implement recent regulations on the identification and management of concussion in school sports during the 2011–2012 school year. To date, 262 school districts, 17 charter schools, and 31 private schools have confirmed that they have put in place policies complying with MDPH regulations. This represents 78 percent of the schools and school districts required to provide confirmation.

Injuries and violence also place a large financial burden on mandatory spending programs. The U.S. population is aging rapidly: currently, 35 million Americans are 65 years of age or older, and by 2020 this number is expected to reach 77 million. The majority of adults over age 64 are covered under the Medicare Federal health insurance program. In 2005, about 22 percent of community-dwelling Medicare beneficiaries reported falling in the previous year.⁷ These fall injuries accounted for 17 percent of emergency department visits and 8 percent of hospital admissions. About one quarter of fall injuries were fractures; 4 percent were hip fractures.⁸

According to the CDC, fall injuries are one of the 20 most expensive medical conditions. After adjusting for inflation, the direct medical costs of older adult fall inju-

⁶State of the States: 2011 Report. Atlanta, GA: Safe States Alliance; 2013.

⁷Stevens JA, Ballesteros MF, Mack KA, et al. Gender differences in seeking care for falls in the aged Medicare population. *Am J Prev Med* 2012;59–62.

⁸Carroll NV, Slattum PW, Cox FM. The cost of falls among the community-dwelling elderly. *Journal of Managed Care Pharmacy* 2005;11(4):307–16.

ries in 2011 totaled \$36.4 billion.⁹ Medicare costs in the first year after a fall averaged between \$12,150 and \$18,009. About 58 percent of direct medical costs were for inpatient hospitalizations, with 16 percent for home health care, 10 percent for medical office visits, 8 percent for hospital outpatient visits, 6 percent for emergency room visits, and 1 percent each for prescription drugs and dental visits. Of these costs, about 78 percent were reimbursed by Medicare.⁸ In 2011 dollars adjusted for inflation, the annual cost of falls in 2020 is estimated to be \$61.6 billion.¹⁰

Preventable injuries exact a heavy burden on Americans through premature deaths, disabilities, pain and suffering, medical and rehabilitation costs, disruption of quality of life for families, and disruption of productivity for employers. Strengthening investments in public health injury and violence prevention programs is a critical step to keep Americans safe and productive for the 21st century. The Safe States Alliance would like to thank the Committee for consideration of this testimony.

PREPARED STATEMENT OF THE SCLERODERMA FOUNDATION

Fiscal Year 2014 Appropriations Recommendations:

- Provide \$32 billion for the National Institutes of Health in fiscal year 2014, with corresponding increases to the National Institute of Arthritis, Musculoskeletal and Skin Disease, the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, and the National Institute of Minority Health and Health Disparities.
- The Committee recommendation for the National Institute of Arthritis, Musculoskeletal and Skin Disease to provide sustained investment in the Scleroderma research portfolio which has a proven success in providing insight to the medical and research community's understanding of the disease, as well as other connective tissue diseases.
- The Committee's encouragement of the National Heart, Lung and Blood Institute to expand research related to the pulmonary complications of Scleroderma patients with Systemic sclerosis.

The Scleroderma Foundation:

My name is Robert Riggs, and I am the Chief Executive Officer. On behalf of the Scleroderma Foundation and the estimated 300,000 Americans impacted by the disease, I appreciate the opportunity to submit written testimony to the Senate Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee regarding the Foundation's recommendations for fiscal year 2014 Appropriations for the Department of Health and Human Services.

Given the work of this subcommittee to accommodate the crippling parameters of budget sequestration, long term deficit reduction and recent cuts to non-defense, discretionary spending, I greatly respect the Committee's continued commitment in support of investments in medical research to enhance patient care and sustained funding support for health programs that benefit patients with rare, costly and difficult to treat diseases like Scleroderma.

Based in Danvers, Massachusetts, the Scleroderma Foundation is a non-profit, national organization committed to providing support to the thousands of patients and their families with the disease, promoting public awareness and education for medical professionals and the public about the condition, and supporting both Federal and private research into finding the cause, treatment options and hopefully, a cure for Scleroderma and other connective tissue diseases.

With a network of 23 chapters, more than 150 support groups and a toll-free helpline for patients and their families, the Foundation strives to provide high quality support through peer counseling, physician referrals and educational information. The Foundation supports nearly \$1 million per year in research funding, providing seed money for new and established Scleroderma investigators. Determined by our Peer Research Review Committee of medical experts, this annual investment, which is the largest single expenditure of the Foundation, backs high quality and innovative research at universities, hospitals and laboratories.

Scleroderma:

Scleroderma is a rare, progressive disease that involves the hardening and tightening of the skin and connective tissues. Considered both a rheumatic and connec-

⁹Stevens JA, Corso PS, Finkelstein EA, Miller TR. Cost of fatal and nonfatal falls among older adults. *Inj Prev* 2006;12(5):290-95.

¹⁰Englander F, Hodson TJ, Terregrossa RA. Economic dimensions of slip and fall injuries. *Journal of Forensic Science* 1996;41(5):733-46. *trial. The Gerontologist* 1994;34(1):16-23.

tive tissue disorder, patients experience an overproduction of collagen in the skin, tissue and underlying muscle (localized Scleroderma). Severe cases of Scleroderma also impact internal organs such as the heart, lungs, kidneys, intestines as well as internal systems and blood vessels (Systemic Scleroderma).

Localized Scleroderma primarily impacts the skin, but can also affect the associated tissue and muscles. In localized cases, thickened areas of skin appear lighter or darker than surrounding skin and can develop in patches, which is a type classified as “morphea.” Thickened skin can also appear in abnormally thick bands, or in a “linear” pattern on the arms, legs or face (termed “Scleroderma en coup de sabre”). Most patients with the localized form of the disease improve over time, while a darkened skin appearance and localized muscle weakness, may remain permanently.

Systemic Scleroderma (SSc), which is experienced by approximately one-third of Scleroderma patients, affects the internal organs and systems, blood vessels, as well as the skin. In limited cutaneous systemic sclerosis or CREST syndrome, both the internal and external tightening occurs in strictly the face, hands, forearms, lower legs and feet and patients experience CREST symptoms. CREST symptoms include:

- Cacinos, calcium deposits form in the connective tissues of the hands, face, abdominal area and arms.
- Raynaud’s phenomenon, blood vessels in the hands, but also in the feet contract due to stress, anxiety or cold temperature appearing white or blue.
- Esophageal dysfunction, muscle weakness is experienced in the esophagus resulting in patients experiencing trouble swallowing or heartburn.
- Sclerodactyly, rigid fingers caused by thickened or tight skin, cause patients difficulty in bending or straitening their digits.
- Telangiectasia, the appearance of red spots in the hands and face.

Diffuse cutaneous scleroderma affects large areas of skin as well as the esophagus, gastrointestinal tract, lungs, kidneys, heart, and joints and occurs with a sudden onset. Given the impact of the fibrous collagen development and the long term impact within the associated internal organs, individuals with the diffuse form of Scleroderma often experience more serious long term patient prognoses and life threatening complications. These patients are at risk of developing pulmonary fibrosis or hypertension, heart issues such as cardiomyopathy, arrhythmia or myocarditis, kidney disease, and gastrointestinal issues in the esophagus and intestines. While Scleroderma can affect anyone regardless of age, race, ethnicity or gender, there is an increased incidence amongst women and minorities. Typically women are three times more likely to experience Scleroderma and African Americans, Native Americans and other minority patient communities are more likely to be diagnosed with Systemic Scleroderma. In most cases, the localized form of the disease is more common to children and the average onset of the disease is between the ages of 25 and 55-years-old.

Given the different types, unpredictable and sometimes swift progression of the disease, and its rarity, Scleroderma, like many other autoimmune diseases is difficult for medical practitioners to accurately diagnose. Diagnosis requires specialized tests and consultation with rheumatologists, dermatologists and other specialists depending on the disease progression. Furthermore, given the unique experience of each patient’s disease progression, treatments are determined on a patient-by-patient basis depending on the experienced symptoms.

As there is no cure for the Scleroderma, physicians are left offering treatments which minimize the impact of the disease’s progression and alleviate the symptoms. Skin softening agents, anti-inflammatory medication and exposure to heat, are used for typical skin and tissue symptoms. For patients experiencing the internal effects of the systemic class, physicians work to mitigate the long term impact of the disease on internal organs through specialized and personalized treatments. While researchers and medical experts have yet to determine the cause of Scleroderma, preliminary findings point to a susceptibility gene which indicates a predisposition likely tied to familial history of rheumatic disease. Scleroderma patients however rarely have relatives, either immediate or extended, who also have the disease.

The Importance of Federal Investment in Scleroderma:

Despite this Committee’s likely limited 302 (b) allocation and efforts to reduce Federal debt and deficit spending, Federal funding for science and medical research at the National Institutes of Health has remained a bi-partisan, widely supported, critical national investment. As the Committee faces increased pressure due to the effects of budget sequestration, I urge your continued support of the historical commitment this Committee has made to providing adequate funding for the NIH.

In fiscal year 2012 and the current fiscal year, the National Institutes of Health’s estimated research portfolio for Scleroderma remains \$25 million and consists of

grants funded predominantly at the National Institute of Arthritis, Musculoskeletal and Skin Disease (NIAMS) as well as through the National Heart, Lung and Blood Institute, the National Institute of Allergy and Infectious Diseases, and the National Institute of Minority Health and Health Disparities. Like many successful research portfolios, the proven success of the NIH supported Scleroderma portfolio, has provided translational knowledge into connective tissue diseases along with the medical community's increased understanding of Scleroderma.

The Committee's investment has provided hope to the millions of patients with diseases like Scleroderma which are difficult to diagnose, treat and currently without a cure. I know that within her lifetime, Scleroderma patients like Cynthia Cervantes, a high school junior that was afforded the opportunity to testify before this committee 5 years ago, will benefit from tangible advancements delivered through NIH findings.

As this Committee makes the difficult determination of discretionary spending, I urge your continued support of important health related research and patient care programs at NIH. Thank you again for providing the opportunity to submit written testimony on behalf of the Scleroderma Foundation.

PREPARED STATEMENT OF THE SLEEP RESEARCH SOCIETY

Chairman Harkin and distinguished members of the subcommittee, as you begin to craft the fiscal year 2014 (fiscal year 2014) Labor-HHS-Education appropriation bill, the Sleep Research Society (SRS) is pleased to submit this statement for the record asking you to provide \$32 billion for NIH, including a proportional increase for the National Heart, Lung, and Blood Institute (NHLBI), \$1 million in funding for sleep disorders awareness and surveillance at the Centers for Disease Control and Prevention (CDC), full support for the National Center on Sleep Disorders Research (NCSDR), and implementation of the 2011 NIH Sleep Disorders Research Plan. These actions will ensure increased awareness of the importance of sleep and circadian rhythms and further the advancements being made by sleep researchers to better understand the relationship between sleep and health.

SLEEP RESEARCH SOCIETY

SRS was established in 1961 by a group of scientists who shared a common goal to foster scientific investigations on all aspects of sleep and sleep disorders. Since that time, SRS has grown into a professional society comprising over 1,300 researchers nationwide. From promising trainees to accomplished senior level investigators, sleep research has expanded into areas such as psychology, neuroanatomy, pharmacology, cardiology, immunology, metabolism, genomics, and healthy living. SRS recognizes the importance of educating the public about the connection between sleep and health outcomes. We promote training and education in sleep research, public awareness, and evidence-based policy, in addition to hosting forums for the exchange of scientific knowledge pertaining to sleep and circadian rhythms.

According to an Institute of Medicine's report entitled, "Sleep Disorder and Sleep Deprivation: An Unmet Public Health Problem" (2006), chronic sleep and circadian disturbances and disorders are a very real and relevant issue in today's society as they affect 50–70 million Americans across all demographic groups. Sleep deprivation is a major safety issue, particular in reference to drowsy driving, where it is a factor in 20 percent of motor vehicle injuries. The high prevalence of sleep disorders in every age group poses widespread effects on public health, extending from poor academic performance in children and adolescents to an increased risk of most major illnesses including: obesity, diabetes, hypertension, cardiovascular disease, stroke, depression, bipolar disorder, and substance abuse.

Sleep-disordered breathing, including obstructive sleep apnea, is a detrimental condition affecting 15 percent of the population. Sleep apnea results in excessive daytime somnolence, impaired cognition, an increased frequency of road traffic accidents, hypertension, and cardiovascular disease. Studies show that 85 percent of 725 troops returning home from Afghanistan and Iraq had a sleep disorder and the most common was obstructive sleep apnea (51 percent). Troops also suffer from insomnia, disrupted sleep-wake rhythms, and fatigue related to post-traumatic stress disorder and traumatic brain injury.

NATIONAL INSTITUTES OF HEALTH

Due to the fact that sleep affects, and is affected by most behavioral and biological systems, many institutes and centers at NIH utilize a portion of their funding to support sleep and circadian research. The majority of sleep research is coordinated

by NHLBI, particularly the National Center on Sleep Disorders Research. An appropriation of \$32 billion for NIH is needed to facilitate the continued growth and advancement in the sleep/circadian research portfolio.

The reason NCSDR is housed at NHLBI is due to the important link between sleep disorders and cardiovascular health. NCSDR supports research, health education, and research training related to sleep-disordered breathing and the fundamental function of sleep and circadian rhythms. Furthermore, NCSDR coordinates sleep research across NIH and with other Federal agencies and outside organizations.

NCSDR's coordinating role between institutes is made possible through adequate funding. These research activities also have far reaching effects, beginning with training grants targeted towards undergraduate students and continuing to career development opportunities attracting top research talent in doctoral programs. Sequestration has the potential to disrupt the research training pipeline designed to train future investigators who are pursuing research in sleep disorders and circadian rhythms, by reducing the amount of F, T, and K series awards.

It is also important to recognize that by increasing the Federal commitment to sleep and circadian research, we can improve the health of those brave Americans who have served in uniform and are suffering from sleep disorders. Both obstructive sleep apnea and insomnia have a high prevalence among active-duty U.S. Armed Forces and among Veterans. Post-traumatic stress disorder and/or depression are highly prevalent in returning Iraq and Afghanistan combat Veterans. Sleep disturbance is a prominent symptom in these disorders. Traumatic brain injury is increasingly common in modern combat, and sleep disruption in the aftermath of TBI may have negative effects on long-term recovery of normal brain function.

The Department of Veterans Affairs (VA) has shown a commitment to collaborating with NIH on sleep research related to Post-Traumatic Stress Disorder (PTSD), Traumatic Brain Injury (TBI), and Gulf War Illness (GWI). This is highlighted in the fiscal year 2014 (fiscal year 2014) President's budget request detailing research initiatives in PTSD and TBI. The "Longitudinal Health Study of Gulf War Era Veterans" is one of the largest scientific research studies on chronic diseases and multi-symptom illnesses, including Gulf War Illness. Researchers found that prazosin, an inexpensive drug already used by millions of Americans for hypertension and prostate problems, improves sleep and reduces nightmares for veterans with PTSD. They continue to pursue activities such as the difference between female and male veterans with PTSD and possible intervention strategies to help veterans with TBI return to daily activities. One study described in the Veteran's Health Administration report State of VA Research 2012, found that 96 percent of veterans with chronic multi-symptom illnesses experienced sleep disordered breathing. By using continuous positive airway pressure (CPAP) these veterans reported reductions in pain and fatigue and improvements in cognitive function. It is important to fund NIH in fiscal year 2014 so that we can continue these advancements in sleep and circadian research.

CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC gathers important data on sleep disorders through their surveillance efforts under the Chronic Disease Prevention and Health Promotion program. Most notably, CDC hosts a National Sleep Awareness Roundtable (NSART) by promoting the importance of sleep through the production of State fact sheets, updating the CDC website, and disseminating information on sleep related topics. CDC also promotes awareness of sleep disorders and the dangers associated with sleep deprivation for the benefit of millions of Americans. Currently population-based data on the prevalence of circadian disruption and its relationship to disease risk is relatively limited. Please fund CDC at \$7.8 billion including an allocation of \$1 million solely for sleep awareness and surveillance activities within the Chronic Disease Prevention and Health Promotion program so that progress can continue in the areas of sleep disorders and disturbances, sleep awareness, and education to the public community.

NIH SLEEP DISORDERS RESEARCH PLAN

NCSDR published the NIH Sleep Disorders Research Plan in November of 2011 highlighting the implementation of pertinent sleep research goals to enable further advancements in the realm of sleep and circadian rhythm disorders. A Joint Task Force between the two leading organizations representing the sleep medicine and research community, Sleep Research Society (SRS) and American Academy of Sleep Medicine (AASM), has identified research opportunities within the plan that will have the highest impact on health, including:

- Reducing the societal impact of sleep deficiency and circadian dysfunction on health
- Identifying key effective treatments for sleep and circadian disorders across the lifespan
- Enhancing the training pipeline for future sleep and circadian researchers
- Developing academic sleep and circadian research networks

Research activities and stakeholders addressed by the plan benefit from the encompassing range of NIH research, training and outreach programs. Over the past 2 years, steps have been taken to implement portions of this research plan, but additional work needs to be done. SRS encourages you to recommend that this research plan continue to be implemented during fiscal year 2014.

Thank you for the opportunity to submit the views of the sleep research community. Please do not hesitate to contact us should you have any questions or require additional information.

PREPARED STATEMENT OF THE SOCIETY FOR MATERNAL-FETAL MEDICINE

On behalf of the Society for Maternal-Fetal Medicine (SMFM), I am pleased to submit testimony in support of funding for the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). We urge your support of at least \$32 billion for NIH, including \$1.37 billion for NICHD in fiscal year 2014.

Established in 1977, SMFM is dedicated to improving maternal and child outcomes and raising the standards of prevention, diagnosis, and treatment of maternal and fetal disease. Maternal-fetal medicine specialists, known as MFM specialists, perinatologists, or high-risk pregnancy physicians, are highly trained obstetricians/gynecologists with advanced expertise in obstetric, medical, and surgical complications of pregnancy and their effects on the mother and fetus. The complex problems faced by some mothers may lead to death as well as short-term or life-long problems for both mothers and their babies. Such complications be understood, treated, prevented and eventually solved through research.

NICHD's mission is to ensure that every child is born healthy and that women suffer no harmful effects from reproductive processes. NICHD-supported basic, clinical, translational, and multidisciplinary research studies address a myriad of issues in pregnancy including:

Preterm birth.—Delivery before 37 weeks' gestation is associated with increased risks of death in the immediate newborn period as well as in infancy, and can cause long-term complications. About 20 percent of premature babies die within the first year of life, and although the survival rate is improving, many preterm babies have life-long disabilities including cerebral palsy, mental retardation, respiratory problems, and hearing and vision impairment. Preterm birth costs the U.S. \$26 billion annually.

Stillbirth.—Defined as the death of a fetus at 20 or more weeks of gestation, stillbirth complicated nearly 26,000 pregnancies in the United States in 2005. Stillbirth is more than twice as common among African Americans as Caucasian women. Other maternal risk factors for stillbirth include advanced age, obesity, and co-existing medical disorders such as diabetes or hypertension. The impact of environmental exposures on stillbirth risk remains unknown. Of known stillbirth causes, the most common are genetic abnormalities, alterations in the number or structure of the chromosomes, maternal infection, hemorrhage, and problems with the umbilical cord or placenta. However, the cause remains unknown in about half of all stillbirths.

Hypertensive diseases in pregnancy.—High blood pressure (hypertension) during pregnancy is the second leading cause of maternal death in the United States, accounting for 15 percent of all deaths. For the mother, it is associated with increased need for delivery because of pregnancy complications, stroke, pulmonary or heart failure, and death. The likelihood and severity of these complications increases as the severity of the hypertension increases, and if preeclampsia develops. Preeclampsia is characterized by high blood pressure and the presence of protein in the urine. Its cause remains one of the greatest mysteries in obstetrics and is a major cause of maternal, fetal, and neonatal mortality worldwide.

Pregestational and gestational diabetes.—The hormonal changes of pregnancy can seriously worsen preexisting diabetes and often bring about a diabetic state (gestational diabetes) in predisposed women. Whether diabetes mellitus existed before conception or gestational diabetes develops during pregnancy, maternal glucose intolerance can have significant medical consequences for both mother and baby. Poorly controlled diabetes is associated with miscarriage, congenital malformations, abnormal fetal growth, stillbirth, obstructed labor, increased cesarean delivery, and

neonatal complications. Up to 200,000 pregnancies are affected by gestational diabetes each year.

Great strides are being made through NICHD-supported research to address the complex situations faced by mothers and their babies. One of the most successful approaches for testing research questions is the NICHD research networks which allow researchers from across the country to collaborate and coordinate their work to change the way we think about pregnancy complications and change medical practice across the country. These networks deal with different aspects of pregnancy: the problem of preterm birth and its consequence.

The Stillbirth Collaborative Research Network (SCRN) was created to study the extent and causes of stillbirth in the United States, and is conducting a geographic population-based determination of the incidence of stillbirth and is determining the causes of stillbirth using a standardized protocol that includes clinical histories, autopsies and pathologic examinations of the fetus and placenta as well as other post-mortem tests to illuminate genetic, maternal and environmental influences. The information from this Network will benefit families who have experienced a stillbirth, women who are pregnant or who are considering pregnancy, and obstetric care providers. In addition, the knowledge gained from this Network will support future research aimed at improving preventive and therapeutic interventions and at understanding the mechanisms that lead to fetal death.

Another important network is the Maternal-Fetal Medicine Units Network (MFMU), established in 1986 to achieve a greater understanding and pursue development of effective treatments for the prevention of preterm births, low birth weight infants and medical complications during pregnancy. The MFMU Network has identified new effective therapies and will put an end to practices that are not useful. It is the only national research infrastructure capable of performing the much needed large trials that provide the evidence on which sound medical practice is based. The MFMU Network is also the ideal vehicle to collaborate with other NIH networks, as well as international networks in order to improve global health. Since its inception, the Network has made several exciting scientific advancements and has been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures that directly benefit those affected.

Following a series of studies in the 1970s and 1980s, an MFMU Network clinical trial showed that progesterone treatment resulted in a substantial reduction in the rate of preterm delivery among women who had a previous preterm birth, reduced the risk of newborn complications, and was effective in both African American and Non-African American women. The MFMU Network conducted the largest, most comprehensive trial to date to test whether magnesium sulfate given to a woman in labor with a premature fetus (24 to 31 weeks out of 40) would result in a reduction in cerebral palsy. In August 2008, NIH announced that magnesium sulfate, when administered to women at risk of imminently delivering preterm, reduces the risk of cerebral palsy in surviving preterm infants by 45 percent.

The MFMU Network provided the first conclusive evidence that treating pregnant women who have even the mildest form of gestational diabetes can reduce the risk of common birth complications among infants, as well as blood pressure disorders among mothers. These findings will change clinical practice and lead to better outcomes for both mothers and babies. Vigorous support of the MFMU Network is needed so that therapies and preventive strategies that have significant impact on the health of mothers and their babies will not be delayed. Until new options are created for identifying those at risk and developing cause specific interventions, preterm birth will remain one of the most pressing problems in obstetrics.

The NuMoM2b network was developed to use current genomic and proteomic techniques in combination with traditional markers for the prediction of adverse pregnancy outcomes, including preterm birth, preeclampsia, fetal growth restriction, and stillbirth in first pregnancies, since adverse pregnancy outcomes are at increased risk for complications in future pregnancies and over 40 percent of pregnancies in the United States are first pregnancies. The NuMoM2b study of 10,000 women provides the infrastructure for additional multicenter study of sleep disordered breathing in pregnancy. Epidemiologic studies have shown that a woman's health status during pregnancy is associated with her long-term health after pregnancy, suggesting that findings in pregnancy may be a better indicator for determining a woman's future health status than traditional risk factors. The NuMoM2b study could serve as the basis for long-term studies to determine the relationships between adverse pregnancy outcomes and long-term maternal health.

Opportunities for future study include collaborative work by NICHD, NHLBI and NIDDK to more closely study these epidemiologic findings in an effort to identify predictive markers during pregnancy for subsequent heart disease and diabetes; develop tests to evaluate health after pregnancy; and test interventions both during

and after pregnancy that may mitigate risk. Research is the cornerstone for improving our understanding of the physiology and pathophysiology of pregnancy, the interrelationship between the mother and fetus, the impact of medical conditions on pregnancy and the impact of medical diseases and pregnancy outcomes on the long term health of both mother and child. With your support, researchers can continue to peel away the layers of complex problems of pregnancy that have such devastating consequences.

PREPARED STATEMENT OF THE SOCIETY FOR NEUROSCIENCE

Mr. Chairman and members of the subcommittee, my name is Larry Swanson, Ph.D. I am the Milo Don and Lucille Appleman Professor of Biological Sciences at University of Southern California. Over the past 30 years my work has focused on the structure and organization of neural structures involved in motivated and emotional behaviors, as well as the development and wiring diagram of the nervous system more generally. This statement is in support of increased funding for the National Institutes of Health (NIH) for fiscal year 2014.

On behalf of the nearly 42,000 members of the Society for Neuroscience (SfN), thank you for your past support of neuroscience research at the NIH. SfN's mission is to advance the understanding of the brain and the nervous system; provide professional development activities, information and educational resources; promote public information and general education; and inform legislators and other policy-makers.

This is an exciting time to be a part of the neuroscience field. Advances in understanding brain development, imaging, genomics, circuit function, computational neuroscience, neural engineering, and many other disciplines are leading to discoveries that were impossible even a few years ago. These will no doubt help us better understand and treat traumatic brain injury, Alzheimer's disease, Parkinson's disease, Down syndrome, schizophrenia, epilepsy, and post-traumatic stress disorder to name just a few. All told, there are more than 1,000 debilitating neurological and psychiatric diseases that strike over 100 million Americans each year, costing an estimated \$750 billion a year.

SfN is appreciative that President Obama recognizes brain science as one of the great scientific challenges of our time. The recently announced Brain Research through Application of Innovative Neurotechnologies (BRAIN) Initiative would enable NIH and other Federal agencies to develop initial tools and conduct further planning that will help accelerate fundamental discoveries and improve the health and quality of life for millions of Americans.

The field of neuroscience is poised to make revolutionary advances thanks to decades of global investment and path-breaking research. However, realizing this potential means today's critical seed funds must be backed by sustained, robust investment in the scientific enterprise in the coming decade. SfN is encouraged by the President's request for a modest increase to the budget of NIH. However, flat funding over the last decade has led to the loss of approximately 20 percent of NIH's purchasing power due to inflation, thus hampering the pursuit of the knowledge needed to uncover the mysteries behind biological function, causes of disease, and potential therapies.

Now is the time to take advantage of scientific momentum, to pave the way for improved human health, to advance scientific discovery and innovation, and to promote America's near-term and long-range economic strength. That requires robust investments in NIH that reverse the tide of stagnant and shrinking funding. These investments contribute to the economic growth of local communities in every State as part of the approximately 85 percent of the NIH budget that goes to funding extramural research. In 2012 alone, NIH supported more than 402,000 jobs and \$57.8 billion in economic output nationwide. Moreover, adequate funding will help preserve and expand America's role as a preeminent leader in biomedical research, supporting public and private institutions and fostering activity in the pharmaceutical, biotechnology, and medical device industries.

Seizing this moment can only happen if labs are able to pursue promising leads and innovative ideas can move forward. A constricted fiscal environment—compounded by sequestration—will stand in the way of that progress. It's impossible to say what breakthroughs will go undiscovered, but there is no doubt that this fiscal environment will result in delayed discoveries, with potentially huge opportunity costs for human health.

Last year, the Society stood with others in the research community in requesting at least \$32 billion for NIH. Today, the need is no less as the funding situation is even more precarious, and the Society urges Congress to reverse the current course

and find ways to invest more in biomedical research. We urge Congress to act before sequestration takes full effect, further eroding the short and long-term capacity for discovery. Let's work to put biomedical research on a trajectory of sustained growth that recognizes its promise and opportunity as a tool for economic growth and, more importantly, for advancing the health of Americans.

BRAIN RESEARCH AND DISCOVERIES

NIH-funded basic (also known as fundamental) research continues to be essential for discoveries that will inspire scientific pursuit and medical progress for generations to come. Past NIH supported projects have helped neuroscientists make tremendous strides in diagnosing and treating neurological and psychiatric disorders. Given the long-term path of basic science and industry's need for shorter-term return on investment, private industry depends on federally-funded research to create a strong foundation for applied research. More than ever, it is important to support and fund research at levels from the most basic to translational.

The following are just three of the many basic research success stories in neuroscience emerging now thanks to strong historic investment in NIH and other research agencies:

A New Model for Complex Brain Disease

A new development from basic science shows tremendous potential for improving understanding of complex diseases such as Alzheimer's, which affects 5.4 million Americans and costs the United States \$200 billion in direct costs annually.

Traditionally, human disease is modeled by identifying and studying single gene mutations that run in families. Brain cells from mice genetically engineered to express this mutated gene can be studied to help illuminate the complex interactions that produce the disease.

Unfortunately for the ease of understanding these diseases, single gene mutations are not the only way to develop most diseases. With Alzheimer's disease, most cases are likely caused by mutations in many different genes. Thus, current models of Alzheimer's likely paint an incomplete picture of the disease.

New developments in stem cell technology are changing this picture. Stem cells are special cells that have the potential to become any other type of cell in the body. Due to advances in genetic engineering, scientists can now trick almost any cell into becoming a stem cell. This technique can be used to turn skin cells from patients with idiopathic Alzheimer's disease into brain cells. These cells are ostensibly identical to the cells in that person's brain, complete with that person's unique genetic risk profile. Research with these cells could potentially help identify subgroups of patients who will respond differently to treatment in clinical trials.

For now, it is not clear whether the brain cells made from this technique are completely identical to the 70-year-old neurons in the brain of a patient with Alzheimer's disease. In addition, these cells are currently prohibitively difficult to create, making them unlikely to replace embryonic stem cells in other applications in the near future. Continued research funding will allow scientists to begin addressing these and other outstanding questions. This research exemplifies the powerful potential to apply basic research well beyond its original intent.

The "Connectome"

Current knowledge about the intricate patterns connecting brain cells (the "connectome") is extremely limited. Yet identifying these patterns and understanding the fundamental wiring diagram or architectural principles of brain circuitry is essential to understanding how the brain functions when healthy and how it fails to function when injured or diseased. Recent research suggests that some brain disorders, like autism and schizophrenia, may result from errors in the development of neural circuits. This research suggests a new category of brain disorders called "disconnection" syndromes.

Advanced technologies, along with faster and more data-efficient computers, now make it possible to trace the connections between individual neurons in animal models providing us with greater insight into brain dysfunction in mental health disorders and neurological disease. Scientists have already used these technologies to examine disease-related circuitry in rodent studies of Parkinson's disease. Their findings helped explain how a new treatment called deep brain stimulation works in people, and are being explored for treatments of other diseases.

Genetics of Schizophrenia

Antipsychotic drugs and improved therapeutic techniques represent great advances in the treatment of schizophrenia, but they do not help everyone. Even when

successful, they typically mitigate only psychotic effects, leaving many severely disabled due to other symptoms.

One promising line of research deals with the genetics of schizophrenia. In recent years, neuroscientists have found numerous mutations linked to schizophrenia. However, no single mutation seems to directly lead to schizophrenia, making a genetic test for the condition unlikely for now. Rather, multiple, rare mutations seem to combine to make someone susceptible. These genes seem to affect neural development and neural plasticity—the ability of the brain to reshape its connections as needed.

One of these genes is the Disrupted-In-Schizophrenia-1 (DISC1) gene. DISC1 helps maintain signaling levels of a key chemical in the brain called glutamate. Mice with a mutant form of DISC1 have reduced glutamate signaling and behavioral abnormalities. There is evidence that this deficit is the result of alterations during development which nonetheless have lasting effects later in life.

Knowing the mechanisms by which individual genes may raise or lower the risk of developing certain diseases is an important first step in identifying the pathways involved in those diseases. Future research is needed to probe the complex interactions of multiple genes within a system. Once pathways are identified, they can provide direction for development of new treatments.

THE FUTURE OF AMERICAN SCIENCE

As the subcommittee considers this year's funding levels, please consider that significant advancements in the biomedical sciences often come from young investigators. The current funding environment is taking a toll on the energy and resilience of these young people. America's scientific enterprise—and its global leadership—has been built over generations. Without sustained investment, we will quickly lose that leadership. The culture of entrepreneurship and curiosity-driven research could be hindered for decades.

We live at a time of extraordinary opportunity in neuroscience. A myriad of questions once impossible to consider are now within reach because of new technologies, an ever-expanding knowledge base, and a willingness to embrace many disciplines.

To take advantage of the opportunities in neuroscience we need an NIH appropriation that allows for sustained reliable growth. That, in turn, will lead to improved health for the American public and will help maintain American leadership in science worldwide. Thank you for this opportunity to testify.

PREPARED STATEMENT OF THE SOCIETY FOR WOMEN'S HEALTH RESEARCH

The Society for Women's Health Research (SWHR) is pleased to have the opportunity to submit the following testimony urging renewed Federal investment in biomedical research, specifically women's health and sex differences research, within the Department of Health and Human Services (HHS). We request that for fiscal year 2014, Congress fund the following agencies and the office of women's health programs at:

- Agency for Healthcare and Research Quality (AHRQ)—\$430 million
- National Institutes of Health (NIH)—\$32 billion
- Office of Research on Women's Health (ORWH)—\$43.3 million
- HHS Office of Women's Health—\$34.7 million
- CDC Office of Women's Health—\$478,000

SWHR is the thought leader in research on biological differences in disease and is dedicated to transforming women's health through science, advocacy, and education. We believe that sustained funding of a Federal research agenda that is inclusive of biomedical and women's health research programs is absolutely essential if the U.S. is to meet the needs of its citizens, especially women. SWHR realizes that the Federal Government is focused on reducing our Federal deficit; however, proper and sustained investment in health research will ultimately save valuable dollars that are currently wasted on inappropriate treatments and procedures.

Past investments in biomedical research propelled the U.S. into the position of world leader in biomedical research. These investments resulted in the mapping of the human genome and made it possible for scientists to discover the biological and physiological differences between women and men. The study of how these differences impact health and medicine, known as sex based biology has been a fundamental part of SWHR's mission since its inception. This research confirms that biological sex plays an important role in disease susceptibility, prevalence, time of onset and severity. Sex differences are evident in cancer, obesity, heart disease, immune dysfunction, mental health disorders, and many other diseases. Medications can have different effects in woman and men, based on sex specific differences in

absorption, distribution, metabolism and elimination. When translated into medical practice, this research will result in a personalized approach to medicine, which will transform medical practice in the U.S.

National Institutes of Health.—In the past decade, NIH has faced a 20.8 percent decrease in buying power as a direct result of budgetary cuts. More than 83 percent of NIH funding is spent in communities across the Nation, creating jobs at more than 3,000 universities, medical schools, teaching hospitals, and other research institutions in every State. The number of new grants funded by NIH has dropped steadily with declining budgets; and in 2012, the NIH Director, Francis Collins, reported that grant funding was at an all-time low of 20 percent.

A shrinking number of available grants put American scientists out of work. With a limited avenue to secure research funding, scientists will have little choice than to pursue opportunities outside of academic research, resulting in the loss of skilled bench scientists and researchers to countries like China, who continue to heavily invest in research. The U.S. desperately needs these researchers and scientists to meet the needs and challenges of an aging U.S. population. Innovation, which can take years to bear fruit, only occurs with continual research investment. It is estimated that U.S. health spending will account for nearly one-fifth of the U.S. economy by 2021. Given this timeframe, investments made today will just be coming onto the market. Rather than implementing across the board budget cuts that will limit future treatments, SWHR believes that Congress should invest in specific areas of cost savings that will lower the overall cost of healthcare, which is the largest driver of the Federal deficit. Research into new and innovative strategies that are proven to prevent, treat, or cure chronic conditions is perhaps the single most cost effective strategy in reducing our Federal deficit.

SWHR recommends that Congress set, at a minimum, a budget of \$32 billion for NIH for fiscal year 2014. Further we recommend that NIH, with the funds provided, be mandated to report sex/gender differences in all research findings, including those studying a single sex but with explanation and justification. Additionally, NIH's mandate should be expanded to include women in all phases of basic, clinical and medical research. Current practice only mandates sufficient female subjects only in Phase III research, and researchers often miss out on the chance to look for variability by sex in the early phases of research, safety and effectiveness is determined.

Office of Research on Women's Health.—ORWH is the focal point for coordinating women's health and sex differences research at NIH, and supports innovative interdisciplinary initiatives that focus on women's health and sex differences research. ORWH works in collaboration with NIH Institutes and Centers (IC's) to implement their programs and co-fund research that incorporates sex and gender differences into their ongoing studies. ORWH also promotes opportunities for and support of recruitment, retention, re-entry and advancement of women in biomedical careers.

—The Building Interdisciplinary Research Careers in Women's Health (BIRCWH) is an innovative, trans-NIH career development program that provides protected research time for junior faculty by pairing them with senior investigators in an interdisciplinary mentored environment. To date, over 490 scholars have been trained in 39 centers, and 80 percent of those scholars have been female. These centers have produced over 4,800 publications, and have been awarded 346 NIH research grants.

—Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health (SCOR) are designed to integrate basic and clinical approaches to sex and gender research across scientific disciplines. These programs have resulted in over 665 articles, reviews, abstracts, book chapters and other publications.

—The Advancing Novel Science in Women's Health Research (ANSWHR) program promotes innovative new concepts and interdisciplinary research in women's health research and sex/gender differences. ORWH partners with 23 NIH IC's, to broaden all areas of women's health and sex differences research.

—Administrative Supplements for Research on Sex and Gender Differences, is a new trans-NIH initiative to broaden the field of sex and gender differences research. It allows ORWH to leverage on-going grants by adding new dimension to the study.

To allow ORWH's programs and research grants to continue make their impact on research and the public, Congress must direct that NIH continue its support of ORWH and provide it with a \$1 million dollar budget increase, bringing its fiscal year 2014 total to \$43.3 million.

Health and Human Services' Office of Women's Health.—The HHS OWH is the Government's champion and focal point for women's health issues. It works to redress inequities in research, health care services, and education that have historically placed the health of women at risk. Without OWH's actions, the task of trans-

lating research into practice would be only more difficult and delayed. Considering the impact of women's health programs from OWH on the public, we urge Congress to provide an increase of \$1 million for this office, a total of \$34.7 million for fiscal year 2014.

Under HHS, the agencies currently with offices, advisors or coordinators for women's health or women's health research include the Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDC), Agency for Healthcare Quality and Research (AHRQ), Indian Health Service (INS), Substance Abuse and Mental Health Services Administration (SAMHSA), Health Resources and Services Administration (HRSA). These offices do important work, both individually and in collaboration with other offices and Federal agencies to ensure that women receive the appropriate care and treatments in a variety of different areas. In a time of limited budgetary dollars, Congress should invest in offices that promote working in collaboration with other agencies, which shares much needed expertise while avoiding unnecessary duplication. SWHR recommends that they are sufficiently funded to ensure that these programs can continue and be strengthened in fiscal year 2014.

In conclusion, Mr. Chairman, we thank you and this Committee for its support for medical and health services research and its commitment to the health of the Nation. We look forward to continuing to work with you to build a healthier future for all Americans.

PREPARED STATEMENT OF THE SPINA BIFIDA ASSOCIATION

BACKGROUND AND OVERVIEW

On behalf of the estimated 166,000 individuals and their families who are affected by all forms of Spina Bifida—Spina Bifida Association (SBA) appreciates the opportunity to submit public written testimony for the record regarding fiscal year 2014 funding for the National Spina Bifida Program housed at the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC) and other related Spina Bifida initiatives. SBA is a national patient advocacy organization, working on behalf of people with Spina Bifida and their families through education, advocacy, research and service. SBA stands ready to work with Members of Congress and other stakeholders to ensure our Nation mounts and sustains a comprehensive effort to reduce and prevent suffering from Spina Bifida.

Spina Bifida, a neural tube defect (NTD), occurs when the spinal cord fails to close properly within the first few weeks of pregnancy. As the fetus grows—the spinal cord is exposed to the amniotic fluid, which increasingly becomes toxic. It is believed that the exposure of the spinal cord to the toxic amniotic fluid erodes the spine and results in Spina Bifida. There are varying forms of Spina Bifida occurring from mild—with little or no noticeable disability—to severe—with limited movement and function. In addition, within each different form of Spina Bifida the effects can vary widely. Unfortunately, the most severe form of Spina Bifida occurs in 96 percent of children born with this birth defect.

The result of this NTD is that most people with it suffer from a host of physical, psychological, and educational challenges—including paralysis, developmental delay, numerous surgeries, and living with a shunt, which helps to relieve cranial pressure associated with spinal fluid that does not flow properly. As we have testified previously, the good news is that after decades of poor prognoses and short life expectancy, children with Spina Bifida are now living into adulthood and increasingly into their advanced years. These gains in longevity are due to breakthroughs in research, combined with improvements in health care and treatment. However, with this extended life expectancy, people with Spina Bifida now face new challenges, such as finding adult health care providers, education, job training, independent living, health care for secondary conditions, and aging concerns, among others. Fortunately, with the creation of the National Spina Bifida Program in 2003, individuals and families affected by Spina Bifida now have a program at the CDC that relates to their needs.

The daily consumption of 400 micrograms of folic acid by women of childbearing age, prior to becoming pregnant and throughout the first trimester of pregnancy, can help reduce the incidence of Spina Bifida, by up to 70 percent. The CDC calculates that there are approximately 3,000 NTD births each year, of which an estimated 1,500 are Spina Bifida, and, as such, with the aging of the Spina Bifida population and a steady number of affected births annually, the Nation must take additional steps to ensure that all individuals living with this complex birth defect can live full, healthy, and productive lives.

COST OF SPINA BIFIDA

It is important to note that the lifetime costs associated with a typical case of Spina Bifida—including medical care, special education, therapy services, and loss of earnings—are as much as \$1 million. The total societal cost of Spina Bifida is estimated to exceed \$750 million per year, with just the Social Security Administration payments to individuals with Spina Bifida exceeding \$82 million per year. Moreover, tens of millions of dollars are spent on medical care paid for by the Medicaid and Medicare programs. Efforts to reduce and prevent suffering from Spina Bifida will help to not only save money, but will also save—and improve—lives.

IMPROVING QUALITY-OF-LIFE THROUGH THE NATIONAL SPINA BIFIDA PROGRAM

Since 2001, SBA has worked with Members of Congress and staff at the CDC to help improve our Nation's efforts to prevent Spina Bifida and diminish suffering—and enhance quality-of-life—for those currently living with this condition. With appropriate, affordable, and high-quality medical, physical, and emotional care, most people born with Spina Bifida will likely have a normal or near normal life expectancy. The CDC's National Spina Bifida Program works to improve quality-of-life for those living with Spina Bifida.

The National Spina Bifida Program helps provide information and support to help ensure that individuals, families, and other caregivers, such as health professionals, have the most up-to-date information about effective interventions for the myriad primary and secondary conditions associated with Spina Bifida. Among many other activities, the program helps individuals with Spina Bifida and their families learn how to treat and prevent secondary health problems, such as bladder and bowel control difficulties, learning disabilities, depression, latex allergies, obesity, skin breakdown, and social and sexual issues. Children with Spina Bifida often have learning disabilities and may have difficulty with paying attention and executive function skills such as math. These problems can be treated or prevented, but only if those affected by Spina Bifida—and their caregivers—are properly educated to provide the skills leading to the highest level of health and well-being possible. The National Spina Bifida Program's secondary prevention activities represent a tangible quality-of-life difference to the estimated 166,000 individuals living with all forms of Spina Bifida, with the goal being living well with Spina Bifida.

An important resource to better determine best clinical practices and the most cost effective treatments for Spina Bifida is the National Spina Bifida Patient Registry, now in its third year. A total of 17 sites throughout the Nation have collated over 3000 patient records from which lifesaving data about treatment and care can be extracted.

SBA understands that the Congress and the Nation face unprecedented budgetary challenges. However, the progress being made by the National Spina Bifida Program must be sustained to ensure that people with Spina Bifida—over the course of their lifespan—have the support and access to quality care they need and deserve. To that end, SBA respectfully urges the subcommittee to Congress allocate \$5.812 million (level funding) in fiscal year 2014 to the program, so it can continue its current its current scope of work, increase its folic acid awareness/Spina Bifida prevention efforts, further develop the National Spina Bifida Patient Registry, and ensure that patients and their clinicians receive the most up-to-date information—all efforts that help improve quality of life and fulfill unmet needs for an estimated 166,000 Americans currently living with Spina Bifida.

SUSTAIN AND SEIZE SPINA BIFIDA RESEARCH OPPORTUNITIES

Our Nation has benefited immensely from our past Federal investment in biomedical research at the NIH. SBA joins with other in the public health and research community in advocating that NIH receive increased funding in fiscal year 2014. This funding will support applied and basic biomedical, psychosocial, educational, and rehabilitative research to improve the understanding of the etiology, prevention, cure and treatment of Spina Bifida and its related conditions. In addition, SBA respectfully requests that the subcommittee include the following language in the report accompanying the fiscal year 2014 LHHS appropriations measure:

“The Committee encourages NIDDK, NICHD, and NINDS to study the causes and care of the neurogenic bladder in order to improve the quality of life of children and adults with Spina Bifida; to support research to address issues related to the treatment and management of Spina Bifida and associated secondary conditions, such as hydrocephalus; and to invest in understanding the myriad co-morbid conditions experienced by children

with Spina Bifida, including those associated with both paralysis and developmental delay.”

CONCLUSION

Please know that SBA stands ready to work with the subcommittee and other Members of Congress to advance policies and programs that will reduce and prevent suffering from Spina Bifida. Again, we thank you for the opportunity to present our views regarding fiscal year 2014 funding for programs that will improve the quality-of-life for the estimated 166,000 Americans and their families living with all forms of Spina Bifida.

PREPARED STATEMENT OF THE TRANSPLANT ROUNDTABLE

Dear Chairman Harkin and Ranking Member Moran: On behalf of the Transplant Roundtable, a coalition of organ transplant patients, professionals, and related organizations, the undersigned organizations offer our strong support for Federal funding for the organ donation and transplantation programs run by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA).

We applaud you for your many years of unwavering commitment to these programs and ask again for your assistance. While we recognize the serious challenges regarding the Federal budget, it is critical that the Federal Government retain its strong commitment to these programs. As such, we ask that you preserve, at a minimum, a level budget of \$24 million for these DoT programs from fiscal year 2013 to fiscal year 2014.

The DoT serves a unique and irreplaceable function and if discretionary funds are available, an increase in funding (i.e., \$3 million) for fiscal year 2014 would make a huge difference and ultimately save lives. DoT provides oversight and funding for the Nation's organ procurement, allocation, and transplantation system through the Organ Procurement and Transplantation Network (OPTN). It coordinates all organ and tissue donation activities and funds donation research. Further, through the National Living Donor Assistance Center (NLDAC), it provides funding for travel and subsistence expenses of living donors whose low income may otherwise prohibit them from donating. These and other programs funded through DoT are very worthy of additional Federal investment as they produce a major return on this investment, year after year.

DoT reports that each day, an average of 79 people receive organ transplants; however, an average of 18 people die each day waiting for transplants that do not occur because of the shortage of donated organs. As of February 2013, the national patient waiting list for organ transplants contained more than 127,000 listings. The total number of transplants from January to November of 2012 was approximately 26,000, with nearly 13,000 donors during that same time period.

Congressional, agency and private sector support has resulted in transplantation that has saved and enhanced the lives of more than 600,000 people in the United States, helped to greatly reduce the number of deaths on the waiting list, and generated substantial savings to the Medicare program through foregone need for dialysis. As a country, we do very well in facilitating and providing these life-saving services, but we need sustained Federal commitment and resources to continue this mission.

Your leadership has been exemplary over many years on transplantation and organ donation activities. On behalf of transplant patients and their families, we ask that you again champion Federal organ donation and transplantation programs run through HRSA.

Sincerely,

Alliance for Paired Donation, American Association of Kidney Patients, American Association for the Study of Liver Diseases, American Society of Nephrology, American Society of Pediatric Nephrology, American Society of Transplantation, American Society of Transplant Surgeons, American Transplant Foundation, Association of Organ Procurement Organizations, Dialysis Patient Citizens, Eye Bank Association of America, NATCO, The Organization for Transplant Professionals, National Kidney Foundation, PKD (Polycystic Kidney Disease) Foundation, Renal Physicians Association, Texas Transplant Society, Transplant Recipients International Organization, United Network for Organ Sharing.

PREPARED STATEMENT OF THE TREVOR PROJECT

Dear Chairman Harkin and Representative Moran: My name is Abbe Land, and I am the Executive Director and CEO. The Trevor Project appreciates the opportunity to submit a statement on the critical and timely issue of funding for children's mental health initiatives. We strongly encourage you to support our Nation's youth by funding these vital programs:

- Increase and continue to fund SAMHSA Mental Health Programs: \$1.101 billion
- Continue to fund and reauthorize the Garrett Lee Smith Memorial Act, and increase funding by \$2 million to each program (\$44 million total, SAMHSA)
- Now is the Time Programs (Departments of Justice, Education, HHS):
 - Authorize \$150 million for the Comprehensive School Safety Program
 - Authorize \$80 million to help create safer and healthier school climates
 - Fully fund Project Aware—\$155 million (Department of Education, HHS)
- Continue to support and fund the Elementary and Secondary School Counseling Program (Department of Education): \$52.3 million
- Continue to fund and reauthorize the Runaway and Homeless Youth Act and increase funding to \$165 million (Department of Housing and Urban Development)
- Continue to fund the Prevention and Public Health Fund (Departments of Health and Human Services, SAMHSA):
 - Behavioral Health Screening and Integration with Primary Health—\$70 million
 - Public Health Workforce—\$45 million
- Restore and augment funding to the Centers for Disease Control and Prevention, Division of Adolescent and School Health: \$50 million

The Trevor Project is the leading national organization providing crisis intervention and suicide prevention services to lesbian, gay, bisexual, transgender and questioning (LGBTQ) young people under 24. The Trevor Project saves young lives through its free and confidential lifeline, a secure instant messaging service providing live help, in-school workshops, educational materials, online resources and advocacy. Recognized by the President as a Model of Pride, The Trevor Project has been an innovator in suicide prevention since 1998.

The recent tragic and senseless loss of life in Newtown, Connecticut, has highlighted the need for action to address the serious mental health concerns that continue to face our Nation. President Obama has brought further attention to this critical issue through his "Now is the Time" Presidential plan,¹ which emphasizes the importance of both mental health care and safe schools as part of an effort to protect our youth and communities. We thank the Committee for taking a thorough look at the funding mechanisms that support our Nation's youth mental health programs, and we hope that this letter will identify the critical programs that exist to protect our most vulnerable youth.

While Congress has sought to increase access to appropriate mental health care in recent years through the passage of laws such as the Mental Health Parity and Addiction Equity Act and the Affordable Care Act, there unfortunately remain substantial barriers to accessing mental health care, particularly for young people.

According to the National Survey of Children's Health, up to 20 percent of young people have a diagnosable mental illness, but only 60 percent of those in need of mental health care receive the treatment they require.² In fact, half of all individuals with mental illness experience onset of the disorder by age 14, but do not seek treatment, on average, until the age of 24.³ For youth, the consequences of untreated mental illness vary and include increased suicide risk, school failure, involvement in the criminal justice system, unemployment, substance abuse, and homelessness. Among stigmatized populations such as LGBTQ young people, these negative outcomes can be exacerbated by prejudice, fear, and hate experienced in homes, schools, and communities.

¹ The White House, *Now is the Time: The President's plan to protect our children and communities by reducing gun violence* (2013).

² 2007 *National Survey of Children's Health*, Data Resource Center for Child & Adolescent Health, Child and Adolescent Health Measurement Initiative, <http://www.nschedata.org> (last visited May 2009).

³ Ronald C. Kessler et al., *Lifetime Prevalence and Age-of-Onset Distributions of DSM-IV Disorders in the National Co-morbidity Survey Replication (NCSR)*, 62 *General Psychiatry* 593 (2005); and Philip S. Wang et al., *Failure and Delay in Initial Treatment Contact After First Onset of Mental Disorders in the National Co-morbidity Survey Replication (NCS-R)*, 62 *General Psychiatry* 603 (2005).

Suicidality is closely associated with mental illness; more than 90 percent of those who die by suicide have a diagnosable mental disorder.⁴ Therefore suicide prevention is an essential component of a comprehensive mental health system. Among young people ages 10 to 24, suicide is the second leading cause of death.⁵ This issue is especially critical for LGBTQ youth populations. Research has shown that LGB youth are 4 times more likely to attempt suicide than their straight peers, and questioning youth are 3 times more likely.⁶ Nearly half of young transgender people have seriously thought about taking their lives and one quarter report having made a suicide attempt.⁷ While these statistics are tragic, it is important to remember that together we can prevent suicide through education and awareness.

The Trevor Project recommends the following appropriations to improve access to effective mental health care and reduce suicide risk for young people:

MENTAL HEALTH BLOCK GRANTS (SAMHSA)

SAMHSA operates the only Federal programs dedicated to improving systems of care for youth in juvenile justice and special education programs. Through SAMHSA's block grant programs, States provide necessary services to youth and adults facing mental illness and addiction who would not otherwise be able to seek help and get treatment.

- Congress should allocate a minimum of \$1.101 billion in total fiscal year 2013 funding for mental health programs to sustain and improve necessary initiatives.

GARRETT LEE SMITH MEMORIAL ACT (S. 116) (SAMHSA)

Suicide prevention programs for young people are a life-saving and effective means to address the daunting issue of youth suicide. We can help avoid tragedy by appropriately funding programs that focus on extreme harming behaviors and mental illness in young people. Garrett Lee Smith funding currently supports suicide prevention programs in 40 States, 38 tribes, and 85 colleges.

- Ensure the Suicide Prevention Resource Center that houses the National Best Practices Registry and also the evidence base in suicide prevention continues to be funded at \$5 million annually.
- Increase authorization for State and tribal programs to \$32 million annually, an increase of \$2 million.
- Increase authorization for higher education programs to \$7 million annually, an increase of \$2 million.

NOW IS THE TIME PROGRAMS

(DEPARTMENTS OF JUSTICE, EDUCATION, HEALTH AND HUMAN SERVICES)

The President's Now is the Time plan is a profound affirmation of this Administration's commitment to addressing school safety and youth mental health. These programs must be adequately funded in order to fulfill the promise of making our schools and communities safe for all young people.

- Authorize \$150 million for the Comprehensive School Safety Program. This valuable program will help ensure that every student feels supported and safe, by helping school districts hire 1,000 new school mental health professionals and resource officers.
- Authorize \$80 million to help schools create safer and healthier school climates through comprehensive emergency management, and new monitoring systems.
- Fully fund Project AWARE—\$155 million
 - Support innovative, State-based strategies for improving mental health training and responsiveness to mental health emergencies;
 - Put more trained teachers and mental health professionals on the ground;
 - Help school districts make sure students get the referrals they need;

⁴ *Suicide in the U.S.: Statistics and Prevention*, National Institute of Mental Health, available at <http://www.nimh.nih.gov/health/publications/suicide-in-the-us-statistics-and-prevention/index.shtml#Moscicki-Epi> (last visited Mar. 14, 2013).

⁵ Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, Web-Based Injury Statistics Query and Reporting System (WISQARS), available at <http://www.cdc.gov/ncipc/wisqars> (last visited Mar. 14, 2013).

⁶ Laura Kann et al., *Sexual Identity Sex of Sexual Contacts, and Health-Risk Behaviors Among Students in Grades 9–12—Youth Risk Behavior Surveillance, Selected Sites, United States, 2001–2009*, 60(SS07) MMWR 1 (2011), available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6007a1.htm> (last visited Mar. 14, 2013).

⁷ Arnold H. Grossman & Anthony R. D'Augelli, *Transgender Youth and Life-Threatening Behaviors*, 37(5) *Suicide Life Threat Behav.* 527 (2007).

- Underscore the importance of prevention by offering students mental health services for trauma or anxiety, conflict resolution programs, and other school-based violence prevention strategies.

ELEMENTARY AND SECONDARY SCHOOL COUNSELING PROGRAM

(DEPARTMENT OF EDUCATION)

The Department of Education plays a vital role in ensuring that at-risk youth communities have consistent access to mental health services in schools. Congress should support these services through allocation of funding to new mental health in schools initiatives, as well as through a recommitment to programs that have already been successful.

- The Elementary and Secondary School Counseling Program is the only Federal program that helps school districts put mental health professionals in schools. Congress should continue to fund this critical program at current levels (\$55.3 million).

RUNAWAY & HOMELESS YOUTH ACT (RHYA)

(DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT)

An estimated 40 percent of all homeless youth are LGBTQ-identified, often because they are thrown out of their homes or face family rejection. Nearly 2/3 of these young people are likely to attempt suicide at least once. Funding for the RHYA has not significantly increased since 2008, despite a growing population desperately in need of the services provided by this Act. Through the RHYA, Congress ensures funding for community outreach programs, transitional housing and support services, and counseling and reunification guidance for families to be reconnected.

- Congress should fully fund the Runaway and Homeless Youth Act, providing \$165 million to help keep our vulnerable youth safe and healthy.

PREVENTION AND PUBLIC HEALTH FUND

(DEPARTMENT OF HEALTH AND HUMAN SERVICES)

Preventative care results in better health outcomes, and it is cheaper and more cost effective than downstream alternatives. This is especially true for issues relating to mental health and suicide prevention. The Prevention and Public Health Fund represents an opportunity to recognize mental health as a public health issue, and to take meaningful action to give States the support services and infrastructure necessary to treat it as such.

- Congress should continue to fund Behavioral Health Screening and Integration with Primary Health (\$70 million), which in part goes towards expanding suicide prevention activities and screening for substance use disorders, and towards assisting communities with integrating primary care services into publicly-funded community mental health and behavioral health settings.
- Congress should continue to provide funding for the Public Health Workforce (\$45 million) to help communities train public health providers who will advance preventive medicine and improve the access to and quality of health services in medically underserved communities.

DIVISION OF ADOLESCENT AND SCHOOL HEALTH FUNDING (CDC)

The Centers for Disease Control and Prevention (CDC)'s Division of Adolescent and School Health (DASH) provides crucial support services nationally. DASH helps administer the Youth Risk Behavior Surveillance System (YRBSS)—the only instrument utilized at the Federal level to assess the health and education needs of middle and secondary school students in the United States. This survey collects important information about the health and well-being of our Nation's youth, data that helps advocates and policymakers to make better-informed and more effective decisions on behalf young people.

- Congress should fully restore funding to DASH for \$50 million so that important data continue to be collected about at-risk youth and essential student health programs can continue.

CONCLUSION

We thank the Committee for taking the time to fully assess our Nation's mental health care system, and we appreciate the opportunity to provide a written state-

ment. We strongly support efforts to increase access to mental health care for young people, and we urge the Committee to fully support these critical programs.

If you should have any questions regarding this statement, please contact myself or Elliot Kennedy, Government Affairs Counsel, by email at Elliot.Kennedy@thetrevorproject.org.

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

The Tri-Council for Nursing, comprising the American Association of Colleges of Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing, respectfully requests \$251.099 million for the Nursing Workforce Development programs authorized under Title VIII of the Public Health Service Act (42 U.S.C. 296 et seq.) in fiscal year 2014.

The Tri-Council is a long-standing nursing alliance focused on leadership and excellence in the nursing profession. As the Nation restructures its health care system through expanding access to some 30+ million new patients, decreasing cost, and improving quality, an investment must be made to strengthen the nursing workforce. The U.S. Bureau of Labor Statistics (BLS) projects that the profession of registered nurse (RN) will grow 26 percent for the 10-year timeframe between 2010 and 2020, compared to the average growth rate of 14 percent for all occupations.

Notwithstanding our slowed economic recovery, the BLS projects there will be 2 million health care jobs created between 2010 and 2020. This workforce growth is expected to continue as demand for nursing care accelerates in traditional acute care settings and in non-hospital settings such as home care and long-term care. The BLS projections further explain the need for 495,500 replacements in the nursing workforce, bringing the total number of job openings for nurses due to growth and replacements to 1.2 million by 2020.

As our Nation regains its economic foothold, the Tri-Council urges the subcommittee to focus on the larger context of building the nursing capacity needed to meet the rising health care demands of our Nation's population. Starting on January 1, 2011, Baby Boomers began turning 65 at the rate of 10,000 a day. With them comes the amplified call for health care and services of an aging population, which will swell the pressure on the health care system, especially when coupled with near epidemic growth in childhood obesity, diabetes, and other chronic diseases experienced among the country's populations.

Moreover, the acute nurse faculty shortage is one significant reason why schools of nursing across the country turn away thousands of qualified applications each year. The demand for nurses and the faculty who educate them is a serious impediment to improving the Nation's health care needs. Nurses continue to be the largest group of health care providers whose services are directly linked to quality and cost-effectiveness. The Tri-Council is grateful to the subcommittee for your past commitment to Title VIII funding and respectfully asks that you continue to make the long-term investment that will build the nursing workforce necessary to deliver the quality, affordable care envisioned in health reform.

A Proven Solution: Nursing Workforce Development Programs

The Nursing Workforce Development programs, authorized under Title VIII of the Public Health Service Act, have helped build the supply and distribution of qualified nurses to meet our Nation's health care needs since 1964. Over these past 49 years, the original programs, newly added and expanded programs have addressed all aspects of supporting the workforce—education, practice, retention, and recruitment. They have bolstered nursing education at all levels—from entry-level preparation through graduate study—and have provided support for institutions that educate nurses for practice in rural and medically underserved communities. A description of the Title VIII programs and their impact are included below.

—*Advanced Nursing Education (ANE) Programs* (Sec. 811) fund a number of grant activities—including several traineeships—that aim to increase the size and quality of the advanced nursing workforce. Supporting the preparation of RNs in master's and doctoral nursing programs, the ANE grants help prepare our Nation's nurse practitioners, clinical nurse specialists, nurse midwives, nurse anesthetists, nurse educators, nurse administrators, nurses in executive practice, public health nurses, and other nursing specialists requiring advanced nursing education. In fiscal year 2011, these grants supported the education of over 7,800 students—exceeding the program's performance target by 25 percent. The ANE-funded traineeships comprise the Advanced Education Nursing Traineeships (AENT) and the Nurse Anesthetist Traineeships (NAT). Where AENTs aim to increase the number of advanced education nurses trained to

practice as primary care nurse practitioners or nurse midwives, the NATs seek to address the maldistribution of primary care nurse anesthetists in the United States. Performance data for fiscal year 2011 showed that grantees of the AENT and NAT programs provided direct financial support to 11,242 nursing and nurse anesthesia students, exceeding the performance target of 2,910.

—*Nursing Workforce Diversity (NWD) Grants* (Sec. 821) prepare students from disadvantaged backgrounds to become nurses, producing a more diverse nursing workforce. This outcome will help meet the increasing need for culturally aligned, quality health care for the Nation's rapidly diversifying population and help close the gap in health disparities. This program awards grants and contract opportunities to schools of nursing for a variety of clinical training facilities to address nursing educational needs for not only disadvantaged students but also racial and ethnic minorities underrepresented in the nursing profession. Also, the reauthorization of the NWD program under the Patient Protection and Affordable Care Act added the authority to support advanced nursing education. The persistent underrepresentation of racial/ethnic minority groups prompts an initiative targeting efforts to diversify the ranks of nursing faculty. In fiscal year 2011, the program performance data showed that NWD grantees provided scholarships to 1,270 students, exceeding the performance target by 72 percent.

—*Nurse Education, Practice, Quality and Retention (NEPQR) Grants* (Sec. 831, and Sec. 831 A) help schools of nursing, academic health centers, nurse managed health centers, State and local governments to strengthen nursing education programs thereby increasing the size and quality of the nursing workforce. The purposes of the NEPQR are broad and flexible, allowing the program to address emerging needs in nursing workforce development. For example, projects to develop and disseminate collaborative practice models that incorporate the full range of health care workers in team-based care are of certain interest. NEPQR supports infrastructure development to enhance the coordination and capacity building of interprofessional practice and education among health professions across the United States and particularly in medically underserved areas. For other interests, a number of grant activities have been funded to support several legislative purposes such as expanding the size of academic programs that are able to confer a baccalaureate degree of science in nursing (BSN); recruiting and educating individuals as qualified personal and home care aides in occupational shortage and/or high demand areas; training qualified nursing assistants and home health aides to meet the growing health care needs of the aging population; and/or supporting nurse managed health clinics that serve as primary care access points in areas where primary care providers are in short supply. A total of 5,127 BSN students were supported during fiscal year 2011, exceeding the program's performance target by 5 percent. Grantees funded to support the personal and home health aide purpose of the NEPQR program trained a total of 1,366 students during fiscal year 2011; and grantees supporting the nursing assistant and home health aide NEPQR purpose supported a total of 1,810 students.

—*NURSE Corps (formerly known as the Nursing Education Loan Repayment and Scholarship Program)* (Sec. 846, Title VIII, PHSA) provides monies to students that pay up to 85 percent of a student's loan in return for at least 3 years of service in a designated health shortage area or in an accredited school of nursing. The NURSE Corps Loan Repayment Program (LRP) is a financial incentive program under which individual RNs and advanced practice RNs (APRNs) enter into a contractual agreement with the Federal Government to work full-time in a health care facility with a critical shortage of nurses, in return for repayment of qualifying nursing educational loans. The Patient Protection and Affordable Care Act of 2010 amended the NURSE Corps LRP to extend loan repayment to nurse faculty. These awards assist in the recruitment and retention of nurse faculty at accredited schools of nursing by decreasing economic barriers that may be associated with pursuing a career in academic nursing. The NURSE Corps Scholarship Program (SP) offers scholarships to individuals attending accredited schools of nursing in exchange for a service commitment payback in health care facilities with a critical shortage of nurses. The NURSE Corps SP award reduces the financial barrier to nursing education for all levels of professional nursing students, thus increasing the pipeline. A first funding preference is given to qualified applicants who have zero expected family contribution and who are enrolled full-time in an undergraduate nursing program or a Master's nurse practitioners program.

—*Nurse Faculty Loan Program (NFLP)* (Sec. 846 A, Title VIII, PHSA) provides up to 85 percent of loan cancellation if the student agrees to a 4-year teaching

commitment in a school of nursing. In fiscal year 2011, NFLP grantees provided loans to a total of 2,246 students pursuing faculty preparation at the master's and doctoral level, exceeding the program's performance target of 1,510 by 49 percent. NFLP performance data showed that, of the students supported in fiscal year 2011, over 400 graduated at the end of academic year, exceeding the performance target of 275 by 45 percent.

—*Comprehensive Geriatric Education Program (CGEP) Grants* (Sec. 855, Title VIII, PHSA) provide support to nursing students specializing in care for the elderly. These grants may be used to educate RNs who will provide direct care to older Americans, develop and disseminate geriatric curriculum, prepare faculty members, and provide continuing education. Through continuing education activities, fiscal year 2011 grantees of the CGEP program reached over 8,200 trainees and delivered over 1,700 hours of instruction. Performance data showed that CE offerings primarily focused on topics such as geriatric education for direct care providers, palliative and end-of-life care, and health care and older adults.

Our Nation is faced with a growing health care crisis that must be addressed on many fronts. Nurses are an important part of the solution to the crisis of cost, burden of disease, and access to quality care. To meet this challenge, funding of proven Federal programs such as Title VIII will help ease the demand for RNs. The Tri-Council respectfully requests your support of \$251.099 million for the Title VIII Nursing Workforce Development Programs in fiscal year 2014.

PREPARED STATEMENT OF THE TRUST FOR AMERICA'S HEALTH

Trust for America's Health (TFAH), a nonprofit, nonpartisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority, would like to thank you for this opportunity to submit written testimony regarding fiscal year 2014 appropriations. We would also like to give special thanks to Senator Harkin for decades of tireless work to support for prevention and wellness programs in both his roles as Chairman of the Senate Health, Education, Labor, and Pensions (HELP) Committee but this subcommittee as well.

As you craft the fiscal year 2014 Labor, Health & Human Services, Education and Related Agencies (LHHS) appropriations bill, I urge you to include adequate funding for prevention and preparedness programs at the Centers for Disease Control and Prevention (CDC) and other public health agencies.

As a Nation, we face daunting economic and fiscal challenges. To a large degree, these are driven by high health care costs. Indeed, we spend roughly 75 percent of our Nation's annual \$2.5 trillion in health care spending on preventable chronic diseases. Despite this expenditure of scarce resources, we are managing sickness, not preventing it—and are faced with the grim prospect that, if we remain on our current trajectory, our children may be the first in U.S. history to live shorter, less healthy lives than their parents.

Fortunately, the vast majority of our chronic disease burden is preventable through proven approaches that focus primarily on increased physical activity, improved nutrition, and reduced tobacco use. A recent TFAH report estimates that if average body mass index were reduced by five percent, in just 5 years the United States would save \$30 billion and prevent millions of cases of diabetes, heart disease, stroke, arthritis, and cancer. The Prevention and Public Health Fund and National Prevention Strategy provide an important framework on which we can build efforts to put greater emphasis on prevention, turn our "sick care" system into one that provides true health care, and help Americans lead longer, more productive, healthier lives.

The future health of the Nation depends on supporting both investments within the health sector that promote prevention inside and outside the clinic, as well as partnerships between health and crucial partners in education, transportation, housing, and other sectors, and we must maintain our investment in Federal wellness and prevention programs.

We also cannot forget the critical role that CDC and State and local health departments play in protecting us from communicable diseases, bioterrorist threats and natural disasters. That core capacity has been diminished in recent years because of Federal budget cuts and the economic downturn, resulting in a 20 percent loss (48,000 jobs) in the State and local health department workforce.

Meeting these twin challenges of preventing disease and protecting the American people from natural and man-made threats can only occur with continued support for key programs at the CDC—ranging from the Prevention and Public Health Fund

and Community Transformation Grant program to preparedness programs and other funding streams that assure that all health departments have the foundational capabilities to respond to all health threats.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Cuts to the CDC, our Nation's lead public health agency and a critical partner in our long-term efforts to prevent disease and illness have already been stark. Compared to fiscal year 2010, with sequestration the CDC will have seen its budget authority cut by 18 percent over just 3 years. These cuts have played a big part in the aforementioned workforce cuts. Overall, scarce resources means CDC will be forced to make extremely tough, sometimes life and death choices.

THE PREVENTION AND PUBLIC HEALTH FUND

Significant cuts to the Fund contained in the Middle Class Tax Relief and Job Creation Act of 2012 will be compounded with additional cuts under sequestration. To date, the Fund has invested \$2.25 billion since fiscal year 2010 to support State and local public health efforts to transform and revitalize communities, build epidemiology and laboratory capacity to track and respond to disease outbreaks, train the Nation's public health and health workforce, prevent the spread of HIV/AIDS, expand access to vaccines, reduce tobacco use, and help control the obesity epidemic.

Unfortunately, we learned last month that of \$949 million remaining under the Prevention Fund for fiscal year 2013, a significant portion of funding will be diverted to support outreach and education efforts for the federally-administered Health Insurance Marketplace. TFAH supports insurance enrollment as a critical opportunity to ensure people gain access to life-saving and life-extending services, including essential preventive services. However, it is just as important that people have access to the support they need outside the doctor's office to become and remain healthy to potentially avoid those life-threatening health situations. We are concerned that further cuts to the Prevention Fund will compromise our ability to make progress on cost containment, public health modernization and wellness promotion.

As a result, we urge this subcommittee and Congress to fully allocate fiscal year 2014 Prevention and Public Health dollars towards evidence-based programs, include the Community Transformation Grant program (see below), aimed at promoting primary prevention and public health promotion.

COMMUNITY TRANSFORMATION GRANTS

The Community Transformation Grants (CTG) program, administered by the CDC, is one of our best prevention opportunities. CTG grants empower States and localities to address the drivers of chronic disease. Most importantly, it requires communities to create partnerships to achieve sustainable solutions to help make the healthy choice the easy choice. CTGs must deploy strategies that are evidence-based and all grantees have rigorous health outcomes improvement goals that must be met. It is important to note, that as required by law, at least 20 percent of CTG funds must be targeted to reach rural or frontier communities. Even with current levels of funding, only about 4 in 10 Americans are reached by the CTG program. We recommend the Committee allocate \$300 million from the Prevention Fund for the CTG program in fiscal year 2014, which will allow the program to reach millions more Americans.

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

Over the past several years, the Chronic Disease Center at CDC has made progress in an effort to move away from the traditional categorical approach to funding chronic disease prevention and towards more coordinated, cross-cutting strategies. In 2011, CDC awarded coordinated chronic disease State grants to all 50 States to begin to build a core capacity to address common risk factors and implement comprehensive strategies for promoting health. While funding is no longer available for those grants, the Chronic Disease Center at CDC recently released a new funding opportunity announcement (FOA) aimed at integrating prevention approaches for addressing heart disease, obesity, school health, and diabetes.

Diminishing Federal dollars for CDC has meant that not all 50 States receive funding under our existing categorical grants. Coordinated approaches like this can help to ensure that we fund all State health departments to achieve cross-cutting, core chronic disease prevention capacity. Past proposals from President Obama and others have included plans to consolidate budget lines for the Center, another approach that could further aid coordination of national and State chronic disease pre-

vention. However, consolidation would need to be thoughtfully designed so it meaningfully improves our chances of improving health, not just serve as a budget gimmick that will further harm our ability to address our growing chronic disease burden.

NATIONAL CENTER FOR ENVIRONMENTAL HEALTH (NCEH)

Critical programs conducted at the CDC National Center for Environmental Health support our chronic disease prevention and public health preparedness efforts. However, it remains one of the most critically underfunded parts of CDC. Since fiscal year 2009, NCEH funding has been cut approximately 25 percent. In fiscal year 2012, for example, the CDC Healthy Homes and Lead Poisoning Prevention program was nearly eliminated, putting 600,000 children at risk of the terrible effects of lead poisoning. We recommended that you fund NCEH at \$146.151 million in fiscal year 2014 to help begin to rebuild the lead control program and ensure that no additional ground is lost in addressing the environmental causes of disease.

PUBLIC HEALTH EMERGENCY PREPAREDNESS

The State & Local Preparedness & Response Capability program at the CDC supports health departments in preparing for, and responding to, all types of disasters, including bioterror attacks, natural disasters, and infectious disease outbreaks. The centerpiece is the Public Health Emergency Preparedness (PHEP) Cooperative Agreements. PHEP grants support 15 core capabilities, including biosurveillance, community resilience, countermeasures and mitigation, incident management, information management, and surge management. These capabilities are tiered so that grantees can identify areas of greatest need and target their resources accordingly.

TFAH recommends providing \$657.4 million for the CDC State and Local Preparedness line for fiscal year 2014 in line with the authorized amount included in the recently-passed reauthorization of the Pandemic and All-Hazards Preparedness Act (PAHPA). Cuts mean the loss of highly-trained frontline public health preparedness workers, reduction of the number of high-level laboratories, defunding academic and research centers, and eroding training, exercise, planning, epidemiology, and surveillance capacity. Preparedness is dependent on maintaining a well-trained public health workforce, and inconsistent funding results in serious gaps in our ability to respond to new health threats. It is unreasonable to expect our first responders to continue to be able to confront more threats with fewer resources.

CONCLUSION

Investing in disease prevention is the most effective, common-sense way to improve health and help address our long-term deficit. Hundreds of billions of dollars are spent each year via Medicare, Medicaid, and other Federal health care programs to pay for health care services once patients develop an acute illness, injury, or chronic disease and present for treatment in our health care system. A sustained and sufficient level of investment in public health and prevention efforts is essential to reduce high rates of disease and improve health in the United States.

Should you have any questions regarding this written testimony, please do not hesitate to contact: Rebecca Salay, Director of Government Relations, Trust for America's Health, 1730 M Street, NW, Suite 900, Washington, DC 20036, email bsalay@tfah.org.

PREPARED STATEMENT OF THE UNITED NATIONS FOUNDATION

Chairman Tom Harkin, Ranking Member Jerry Moran, and members of the subcommittee, the American Red Cross and the United Nations Foundation appreciate the opportunity to submit testimony in support of measles control activities of the U.S. Centers for Disease Control and Prevention (CDC). The American Red Cross and the United Nations Foundation recognize the leadership that Congress has shown in funding CDC for these essential activities. We sincerely hope that Congress will continue to support the CDC during this critical period in measles control.

In 2001, CDC—along with the American Red Cross, the United Nations Foundation, the World Health Organization, and UNICEF—founded the Measles Initiative, a partnership committed to reducing measles deaths globally. In 2012, the Initiative expanded to include rubella control and adopted a new name, the Measles & Rubella Initiative (the Initiative). The Initiative aims to reach elimination goals for measles, rubella and congenital rubella syndrome. The current UN goal is to reduce global measles deaths by 95 percent by 2015 compared to 2000 estimates, and three of six WHO regions have set rubella control or elimination targets. The Initiative

is committed to reaching these goals by providing technical and financial support to governments and communities worldwide.

The Measles & Rubella Initiative has achieved “spectacular”¹ results by supporting the vaccination of more than 1.1 billion children. Largely due to the Measles & Rubella Initiative, global measles mortality dropped 71 percent, from an estimated 548,000 deaths in 2000 to 158,000 in 2011 (the latest year for which data is available). During this same period, measles deaths in Africa fell by 84 percent. About 430 children still die from measles each day from a virus that can be countered with an effective, inexpensive vaccine; and each year more than 110,000 children are born with congenital rubella syndrome. In May 2012, the 194 member States of the World Health Assembly resolved to endorse the Global Vaccine Action Plan, which affirmed the elimination of measles and rubella by 2020 in at least five of six WHO regions as global goals.

ESTIMATED NUMBER OF GLOBAL MEASLES DEATHS, 2000–2010
[In thousands]

	Number
2000	535.3
2001	528.8
2002	373.8
2003	484.3
2004	331.4
2005	384.8
2006	227.7
2007	130.1
2008	137.5
2009	177.9
2010	139.3

Working closely with host governments, the Measles & Rubella Initiative has been the main international supporter of mass measles immunization campaigns since 2001. The Initiative mobilized more than \$1 billion and provided technical support in more than 80 developing countries on vaccination campaigns, surveillance and improving routine immunization services. From 2000 to 2011, an estimated 10 million measles deaths were averted as a result of these accelerated measles control activities at a donor cost of less than \$200/death averted, making measles mortality reduction one of the most cost-effective public health interventions.

Nearly all the measles vaccination campaigns have been able to reach more than 90 percent of their target populations. Countries recognize the opportunity that measles vaccination campaigns provide in accessing mothers and young children, and “integrating” the campaigns with other life-saving health interventions has become the norm. In addition to measles vaccine, vitamin A (crucial for preventing blindness in under nourished children), de-worming medicine (reduces malnutrition), and insecticide-treated bed nets (ITNs) for malaria prevention are distributed during vaccination campaigns. The scale of these distributions is immense. The Initiative and its partners have supported the distribution of more than 245 million doses of vitamin A, 113 million doses of de-worming medicine, 41 million insecticide-treated bed nets, and 137 million doses of polio vaccine. Doses of oral polio vaccines are frequently distributed during measles campaigns in polio endemic and high risk countries. The delivery of polio vaccines in conjunction with measles vaccines in these campaigns strengthens the reach of elimination and eradication efforts of these diseases. The delivery of multiple child health interventions during a single campaign is far less expensive than delivering the interventions separately, and this strategy increases the potential positive impact on children’s health from a single campaign.

The extraordinary reduction in global measles deaths contributed nearly 25 percent of the progress to date toward Millennium Development Goal #4 (reducing under-five child mortality). However, large outbreaks in several African, European and Asian countries in 2011 and 2012 have put the 2015 measles elimination goals at risk. These outbreaks highlight the fragility of the last decade’s progress. If mass immunization campaigns are not continued, measles deaths will increase rapidly with more than half a million deaths estimated for 2013 alone.

¹ Unpublished data from Measles & Rubella, Annual Report 2012, page 11 (April 2013).

To achieve the 2015 goal and avoid a resurgence of measles the following actions are required:

- Fully implementing activities, both campaigns and strengthening routine measles coverage, in India since it is the greatest contributor to the global burden of measles.
- Sustaining the gains in reduced measles deaths, especially in Africa, by strengthening immunization programs to ensure that more than 90 percent of infants are vaccinated against measles through routine health services before their first birthday as well as conducting timely, high quality mass immunization campaigns.
- Accelerating the introduction of a second dose of measles containing vaccine into the routine immunization program of eligible countries with support from the GAVI Alliance.
- Securing sufficient funding for measles and rubella-control activities both globally and nationally. The Measles & Rubella Initiative faces a funding shortfall of an estimated U.S. \$171 million for 2013–2015. Implementation of timely measles campaigns is increasingly dependent upon countries funding these activities locally. The decrease in donor funds available at a global level to support measles elimination activities makes increased political commitment and country ownership of the activities critical for achieving and sustaining the goal of reducing measles mortality by 95 percent.

If these challenges are not addressed, the remarkable gains made since 2000 will be lost and a major resurgence in measles deaths will occur.

By controlling measles and rubella cases in other countries, U.S. children are also being protected from the diseases. Measles can cause severe complications and death. A resurgence of measles occurred in the United States between 1989 and 1991, with more than 55,000 cases reported. This resurgence was particularly severe, accounting for more than 11,000 hospitalizations and 123 deaths. Since then, measles control measures in the United States have been strengthened and endemic transmission of measles cases have been eliminated here since 2000. However, importations of measles cases into this country continue to occur each year, particularly from Europe. The costs of these cases and outbreaks are substantial, both in terms of the costs to public health departments and in terms of productivity losses among people with measles and parents of sick children. Studies show that a single case of measles in the United States can cost between \$100,000 and \$200,000 to control. The U.S. had 222 measles cases in 2011, the highest in 15 years and Canada experienced a large outbreak of over 800 cases.

The Role of CDC in Global Measles Mortality Reduction

Since fiscal year 2001 and until 2013, Congress has provided between \$43.6 and \$49.3 million annually in funding to CDC for global measles control activities. These funds were used toward the purchase of measles vaccine for use in large-scale measles vaccination campaigns in more than 80 countries in Africa and Asia, and for the provision of technical support to Ministries of Health. Specifically, this technical support includes:

- Planning, monitoring, and evaluating large-scale measles vaccination campaigns;
- Conducting epidemiological investigations and laboratory surveillance of measles outbreaks; and
- Conducting operations research to guide cost-effective and high quality measles control programs.

In addition, CDC epidemiologists and public health specialists have worked closely with WHO, UNICEF, the United Nations Foundation, and the American Red Cross to strengthen measles control programs at global and regional levels, and will continue to work with these and other partners in implementing and strengthening rubella control programs. While it is not possible to precisely quantify the impact of CDC's financial and technical support to the Measles & Rubella Initiative, there is no doubt that CDC's support—made possible by the funding appropriated by Congress—was essential in helping achieve the sharp reduction in measles deaths in just eleven years.

The American Red Cross and the United Nations Foundation would like to acknowledge the leadership and work provided by CDC and recognize that CDC brings much more to the table than just financial resources. The Measles & Rubella Initiative is fortunate in having a partner that provides critical personnel and technical support for vaccination campaigns and in response to disease outbreaks. CDC personnel have routinely demonstrated their ability to work well with other organizations and provide solutions to complex problems that help critical work get done faster and more efficiently.

In fiscal year 2011 and fiscal year 2012, Congress appropriated approximately \$49 million each year to fund CDC for global measles control activities. This amount represents a \$2.7 million decrease from 2010. The American Red Cross and the United Nations Foundation respectfully request a return to fiscal year 2010 funding levels (\$52 million) for fiscal year 2014 for CDC's measles and rubella control activities to protect the investment of the last decade, and prevent a global resurgence of measles and a loss of progress toward Millennium Development Goal #4.

Your commitment has brought us unprecedented victories in reducing measles mortality around the world. In addition, your continued support for this initiative helps prevent children from suffering from this preventable disease both abroad and in the United States.

Thank you for the opportunity to submit testimony.

PREPARED STATEMENT OF THE THE US HEREDITARY ANGIOEDEMA ASSOCIATION

SUMMARY OF FISCAL YEAR 2014 RECOMMENDATIONS

- 1) \$32 billion for the National Institutes of Health (NIH) at an increase of \$1 billion over fiscal year 2012.
 - 2) Continued Focus on Hereditary Angioedema Research and Education at NIH.
 - 3) Funding to create and support the Centers For Disease Control and Prevention's (CDC) to increase awareness efforts for Hereditary Angioedema at CDC.
-

Chairman Harkin, thank you for the opportunity to present the views of the US Hereditary Angioedema Association (US HAEA) regarding the importance of Hereditary Angioedema (HAE) public awareness activities and research.

The US HAEA is a non-profit patient advocacy organization founded in 1999 to help those suffering with HAE and their families to live healthy lives. The Association's goals were, and remain, to provide patient support, advance HAE research and find a cure. The US HAEA provides patient services that include referrals to HAE knowledgeable health care providers, disease information and peer-to-peer support. US HAEA also provides research funding to scientific investigators to increase the HAE knowledge base and maintains an HAE patient registry to support ground-breaking research efforts. Additionally, US HAEA provides disease information materials and hosts forums to educate patients and their families, health care providers, and the general public on HAE.

HAE is a rare and potentially life-threatening inherited disease with symptoms of severe, recurring, debilitating attacks of edema (swelling). HAE patients have a defect in the gene that controls a blood protein called C1-inhibitor, so it is also more specifically referred to as C1-inhibitor deficiency. This genetic defect results in production of either inadequate or nonfunctioning C1-inhibitor protein. Because the defective C1-inhibitor does not adequately perform its regulatory function, a biochemical imbalance can occur and produce an unwanted peptide—called bradykinin—that induces the capillaries to release fluids into surrounding tissues, thereby causing swelling.

People with HAE experience attacks of severe swelling that affect various body parts including the hands, feet, face, airway (throat) and intestinal wall. Swelling of the throat is the most life-threatening aspect of HAE, because the airway can close and cause death by suffocation. Studies reveal that more than 50 percent of patients will experience at least one throat attack in their lifetime.

HAE swelling is disfiguring, extremely painful and debilitating. Attacks of abdominal swelling involve severe and excruciating pain, vomiting, and diarrhea. Because abdominal attacks mimic a surgical emergency, approximately one third of patients with undiagnosed HAE undergo unnecessary surgery. Untreated, an average HAE attack lasts between 24 and 72 hours, but some attacks may last longer and be accompanied by prolonged fatigue.

The majority of HAE patients experience their first attack during childhood or adolescence. Most attacks occur spontaneously with no apparent reason, but anxiety, stress, minor trauma, medical, surgical, and dental procedures, and illnesses such as colds and flu have been cited as common triggers. ACE Inhibitors (a blood pressure control medication) and estrogen-derived medications (birth control pills and hormone replacement drugs) have also been shown to exacerbate HAE attacks.

HAE's genetic defect can be passed on in families. A child has a 50 percent chance of inheriting the disease from a parent with HAE. However, the absence of family history does not rule out the HAE diagnosis; scientists report that as many as 25 percent of HAE cases today result from patients who had a spontaneous mutation

of the C1-inhibitor gene at conception. These patients can also pass the defective gene to their offspring. Worldwide, it is estimated that this condition affects between 1 in 10,000 and 1 in 30,000 people.

PUBLIC AWARENESS AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION

HAE patients often suffer for many years and may be subject to unnecessary medical procedures and surgery prior to receiving an accurate diagnosis. Raising awareness about HAE among healthcare providers and the general public will help reduce delays in diagnosis and limit the amount of time that patients must spend without treatment for a condition that could, at any moment, end their lives.

Once diagnosed, many individuals are able to piece together a family history of mysterious deaths and episodes of swelling that previously had no name. In some families, over many years, this condition has come to be accepted as something that must simply be endured. Increased public awareness is crucial so that these patients understand that HAE often requires emergency treatment and disabling attacks no longer need to be passively accepted. While HAE cannot yet be cured, intelligent use of available treatments can help patients lead a productive life.

In order to prevent deaths, eliminate unnecessary surgeries, and improve patients' quality of life, it is critical that CDC pursue programs to educate the public and medical professionals about HAE in fiscal year 2014.

RESEARCH THROUGH THE NATIONAL INSTITUTES OF HEALTH

In years past, HAE research was conducted at the National Institutes of Health (NIH) through the National Institute of Allergy and Infectious Diseases, the National Institute of Neurological Disorders and Stroke, the National Heart Lung and Blood Institute, the National Institute of Child Health and Human Development, National Center for Research Resources, and the National Institute on Diabetes and Digestive and Kidney Diseases. However, NIH has not engaged in HAE-specific research since 2009, and there is no longer any Federal research as it relates to HAE.

As it may provide greater opportunities for HAE research, we applaud the recent establishment of the National Center for Advancing Translational Sciences (NCATS) at NIH. Housing translational research activities at a single Center at NIH will allow these programs to achieve new levels of success. Initiatives like the Cures Acceleration Network are critical to overhauling the translational research process and overcoming the challenges that plague treatment development. In addition, new efforts like taking the lead on drug repurposing have the potential to speed access to new treatments, particularly to patients who struggle with rare or neglected diseases. As a rare disease community, HAE patients may also benefit from the Therapeutics for Rare and Neglected Diseases (TRND) program, housed at NCATS, as well coordination with the Office of Rare Diseases Research (ORDR). We ask that you support NCATS and provide adequate resources for the Center in fiscal year 2014.

In order to reinvigorate HAE research at NIH, it is vital that NIH receive increased support in fiscal year 2014. US HAEA recommends an overall funding level of \$32 billion for NIH in fiscal year 2014 and the inclusion of recommendations emphasizing the importance of HAE research to learn more about this rare disease and new pathways for appropriate treatment.

Thank you for the opportunity to present the views of the HAE community.

PREPARED STATEMENT OF THE UNITED STATES SENATE

Hon. TOM HARKIN,
*Chairman, Senate Appropriations Subcommittee on Labor,
 Health and Human Services and Education,
 131 Dirksen Senate Office Building,
 Washington, DC 20510*

Hon. JERRY MORAN,
*Ranking Member, Senate Appropriations Subcommittee on Labor,
 Health and Human Services and Education,
 156 Dirksen Senate Office Building,
 Washington, DC 20510*

Dear Chairman Harkin and Ranking Member Moran: We are writing to thank you for your support for the Office of Museum Services (OMS) at the Institute of Museum and Library Services (IMLS) and to urge the Subcommittee to support robust funding for OMS in the Fiscal Year 2014 Labor, Health and Human Services

and Education Appropriations bill. The Office of Museum Services is currently authorized to receive \$38.6 million annually.

The demand for museum services is greater than ever. At a time when school resources are strained and many families cannot afford to travel or make ends meet, museums are working overtime to fill the gaps—providing more than 18 million instructional hours to schoolchildren, bringing art and cultural heritage, dynamic exhibitions and living specimens into local communities, partnering with other nonprofits to encourage national service and volunteerism, and offering free or reduced admission. Museums are part of a robust nonprofit community working to address a wide range of our Nation's greatest challenges, from conducting medical research to hosting supervised visits for the family court system, and from creating energy efficient public buildings to collecting food for needy families.

Unfortunately, museums are struggling significantly in these difficult economic times. They are being forced to cut back on hours, educational programming, community services and jobs. And according to the 2005 Heritage Health Index, at least 190 million artifacts are at risk, suffering from light damage and harmful and insecure storage conditions. Many museums also rely heavily on philanthropic donations to keep admission rates low and provide new exhibitions for their communities.

The Institute of Museum and Library Services (IMLS) is the primary Federal agency that serves the Nation's more than 17,500 museums, and its Office of Museum Services' funding has decreased in recent years. Although the agency has been successful in creating and supporting advancements in areas such as technology, lifelong community learning and conservation and preservation efforts, only a small fraction of the Nation's museums are currently being reached, and many highly rated grant applications go unfunded each year.

In 2010, the Institute of Museum and Library Services was unanimously reauthorized by both the House and Senate. The agency is highly accountable, and its competitive, peer-reviewed grants serve every State. The reauthorization contained several provisions to further support museums, particularly at the State level, but much of the recently authorized activities cannot be accomplished without sustained funding.

We urge the subcommittee to support robust funding for the IMLS Office of Museum Services for Fiscal Year 2014 to support the important work museums are doing in our communities. This vital funding will aid museums of all types—aquariums, arboretums, archaeological museums, art museums, botanical gardens, children's museums, culturally specific museums, historic sites, history museums, maritime museums, military museums, natural history museums, nature centers, planetariums, science and technology centers, zoological parks, and other types of museums—and enable them to continue serving our schools and communities and preserving our cultural heritage for future generations.

Again, we appreciate the subcommittee's prior support for OMS and request this investment to strengthen and sustain the work of our Nation's museums.

Sincerely,

Kirsten E. Gillibrand, Jack Reed, Patrick J. Leahy, Frank R. Lautenberg, Christopher A. Coons, Angus S. King Jr., Richard Blumenthal, Richard J. Durbin, Jeanne Shaheen, Tim Johnson, Martin Heinrich, Charles E. Schumer, Carl Levin, Sherrod Brown, Joe Manchin III, Bernard Sanders, Ron Wyden, Mazie Hirono, Christopher Murphy, Debbie Stabenow, Benjamin L. Cardin, Sheldon Whitehouse, Brian Schatz, Elizabeth Warren.—*United States Senators*

PREPARED STATEMENT OF THE UNITED TRIBES TECHNICAL COLLEGE

For 44 years, with the most basic of funding, United Tribes Technical College (UTTC) has provided postsecondary career and technical education, job training and family services to some of the most impoverished, high risk Indian students from throughout the Nation. With such challenges, some colleges might despair, but we have consistently had excellent retention and placement rates and are a fully accredited institution. We are proud to be equipping our students to take part in the new energy economy in North Dakota and proud to be part of building a strong middle class in Indian Country by training the next generation of law enforcement officers, educators, medical technicians and "Indianpreneurs." We are governed by the five tribes located wholly or in part in North Dakota. We are not part of the North Dakota State college system and do not have a tax base or State-appropriated funds on which to rely. Section 117 Carl Perkins Act funds represent a significant portion of our operating budget and provide for our core instructional programs. The request of the UTTC Board for fiscal year 2014 is:

- \$10 million for base funding authorized under Section 117 of the Carl Perkins Act for the Tribally Controlled Postsecondary Career and Technical Institutions program (20 U.S.C. Section 2327). This is \$1.8 million above the fiscal year 2012 level. These funds are awarded competitively and are distributed via formula.
- \$30 million as requested by the American Indian Higher Education Consortium for Title III–A (Section 316) of the Higher Education Act (Strengthening Institutions program). This is \$5 million above the fiscal year 2012 enacted level.
- Maintain Pell Grants at the \$5,635 maximum award level.

A Few Things of Note About United Tribes Technical College. We have:

- Renewed unrestricted accreditation from the North Central Association of Colleges and Schools, for July 2011 through 2021, with authority to offer all of our full programs on-line. We have 26 Associate degree programs, 20 Certificate and three Bachelor degree programs (Criminal Justice; Elementary Education; Business Administration).
- Services including a Child Development Center, family literacy program, wellness center, area transportation, K–8 elementary school, tutoring, counseling, family and single student housing, and campus security.
- A projected return on Federal investment of 20–1 (2005 study).
- A semester retention rate of 85 percent and a graduate placement rate of 77 percent. Over 45 percent of our graduates move on to four-year or advanced degree institutions.
- Students from 75 tribes; 85 percent of our undergraduate students receive Pell Grants.
- An unduplicated count of undergraduate degree-seeking students and continuing education students of 1200 and a workforce of 360.
- A dual-enrollment program targeting junior and senior high school students, providing them an introduction to college life and offering high school and college credits.
- A critical role in the regional economy. Our presence brings at least \$34 million annually to the economy of the Bismarck region. A North Dakota State University study reports in that the five tribal colleges in North Dakota made a direct and secondary economic contribution to the State of \$181,933,000 in 2012.

Positioning our Students for Success.—UTTC is dedicated to providing American Indians with postsecondary and technical education in a culturally diverse environment that will provide self-determination and economic development for all tribal nations. This means offering a rich cultural education and family support system which emphasizes enhancement of tribal peoples and nations, while simultaneously evaluating and updating our curricula to reflect the current job market. The ramifications of the North Dakota Bakken oil boom are seen throughout the State. We saw the need for more certified welders in relation to the oil boom and so expanded our certified welding program. We are now able to train students for good paying, in-demand welding jobs. Similarly, our online medical transcription program was designed to meet the growing need for certified medical support staff. Other courses reflect new emphasis on energy auditing and Geographic Information System Technology.

We are in the midst of opening up a distance learning center in Rapid City, SD, where there are some 16,000 American Indians in the area. We are also working toward establishment of an American Indian Specialized Health Care Training Clinic.

FUNDING REQUESTS

Section 117 Perkins Base Funding.—Funds requested under Section 117 of the Perkins Act above the fiscal year 2012 level are needed to: 1) maintain 100 year-old education buildings and 50 year-old housing stock for students; 2) upgrade technology capabilities; 3) provide adequate salaries for faculty and staff (who have not received a cost of living increase for the past year and who are in the bottom quartile of salary for comparable positions elsewhere); and 4) fund program and curriculum improvements.

Perkins funds are central to the viability of our core postsecondary educational programs. Very little of the other funds we receive may be used for core career and technical educational programs; they are competitive, often one-time supplemental funds which help us provide the services our students need to be successful. Our Perkins funding provides a base level of support (averaging over the past 5 years in excess of 40 percent of our core operating budget) while allowing the college to compete for desperately needed discretionary funds leading to additional resources annually for the college's programs and support services.

Title III-A (Section 316) Strengthening Institutions.—Among the Title III-A statutorily allowable uses is facility construction and maintenance. We are constantly in need of additional student housing, including family housing. We would like to educate more students but lack of housing has at times limited the admission of new students. With the completion this year of a new Science, Math and Technology building on our South Campus on land acquired with a private grant, we urgently need housing for up to 150 students, many of whom have families.

While we have constructed three housing facilities using a variety of sources in the past 20 years, approximately 50 percent of students are housed in the 100-year-old buildings of what was Fort Abraham Lincoln, as well as housing that was donated by the Federal Government along with the land and Fort buildings in 1973. These buildings require major rehabilitation. New buildings are actually cheaper rehabilitating the old buildings that now house students.

Pell Grants.—We support maintaining the Pell Grant maximum to at least a level of \$5,635. This resource makes all the difference in whether most of our students can attend college. As mentioned above 85 percent of our undergraduate students are Pell Grant recipients. We are glad to learn of the February 6, 2013 report of the Congressional Budget Office that the Pell Grant program is currently financially healthy and can support full funding the maximum award levels for fiscal years 2013 and 2014.

GOVERNMENT ACCOUNTABILITY OFFICE REPORT

As you know, the Government Accountability Office (GAO) in March of 2011 issued two reports regarding Federal programs which may have similar or overlapping services or objectives (GAO-11-318SP of March 1 and GAO-11-474R of March 18). Funding from the Bureau of Indian Education (BIE) and the Perkins Act for Tribally Controlled Postsecondary Career and Technical Institutions were among the programs listed in the supplemental report of March 18, 2011. The GAO did not recommend defunding these or other programs; in some cases consolidation or better coordination of programs was recommended to save administrative costs. We are not in disagreement about possible consolidation or coordination of the administration of these funding sources so long as funds are not reduced.

Perkins funds represent on average over 40 percent of UTTC's core operating budget. These funds supplement, but do not duplicate, the BIE funds. It takes both sources of funding to frugally maintain the institution. Even these combined sources do not provide the resources necessary to operate and maintain the college. Therefore, UTTC actively seeks alternative funding to assist with curricula, deferred maintenance, and scholarship assistance, among other things.

We reiterate that UTTC and other tribally-chartered colleges are not part of State educational systems and do not receive State-appropriated general operational funds for their Indian students. The need for postsecondary career and technical education in Indian Country is so great and the funding so small, that there is little chance for duplicative funding.

There are only two institutions targeting American Indian/Alaska Native career and technical education and training at the postsecondary level—United Tribes Technical College and Navajo Technical College. Combined, these institutions received less than \$15 million in fiscal year 2012 Federal operational funds (\$8 million from Perkins; \$7 million from the BIE). That is a very modest amount for two campus-based institutions which offer a broad (and expanding) array of training opportunities.

UTTC offers services that are catered to the needs of our students, many of whom are first generation college attendees and many of whom come to us needing remedial education and services. Our students disproportionately possess more high risk characteristics than other student populations. We also provide services for the children and dependents of our students. Although BIE and Section 117 funds do not pay for remedial education services, we make this investment through other sources to ensure our students succeed at the postsecondary level.

Thank you for your consideration of our requests.

PREPARED STATEMENT OF THE UNIVERSITY OF NORTH DAKOTA AND NORTH DAKOTA STATE UNIVERSITY

On behalf of the University of North Dakota (UND) and North Dakota State University (NDSU), thank you for the opportunity to submit our written testimony regarding the fiscal year 2014 funding for the National Institutes of Health (NIH) Institutional Development Award (IDeA) program. We respectfully request your support of no less than \$310.0 million for this critically important program. We further

request that the subcommittee give serious consideration to legislative language which would direct that future NIH budgets include funding for the IDeA program that reaches no less than 1 percent of the total NIH budget. IDeA was authorized by the 1993 NIH Revitalization Act (Public Law 103-43) and funds only merit-based, peer-reviewed research that meets NIH research objectives in the 23 IDeA States and Puerto Rico.

The States eligible for IDeA funding are defined as “all states/commonwealths with a success rate for obtaining NIH grant awards of less than 20 percent over the period of 2001–2005 or received less than an average of \$120 million per year during that time period.” Currently this includes 23 States and Puerto Rico—nearly half of the States. Funding from this capacity-building program has been a key part of the growth in research capacity and impact at the two North Dakota research universities in recent years.

Funding for the IDeA program in fiscal year 2013 was \$ 277.65 million. The total budget for NIH in fiscal year 2013 was \$29.6 billion; thus in fiscal year 2013, the IDeA program—funding competitively awarded biomedical research in nearly half the nation—comprised only 0.94 percent of the entire NIH budget. The IDeA program exists because the 23 eligible States overall receive less than 20 percent of NIH’s extramural funding. The proposed reduction in the President’s fiscal year 2014 budget request of \$52.1 million represents a staggering 18.8 percent cut to the budget of the IDeA program, but represents only 0.18 percent of the entire proposed NIH budget. Making such a serious, disproportionate cut to a program designed to aid small, rural States is manifestly unfair. This program is small in the overall scheme of things at NIH, but huge for the States that compete for these funds. Our requested funding level of \$310.0 million represents only 0.99 percent of the President’s total fiscal year 2014 budget request for NIH.

Our State, North Dakota, has benefited immensely from the competitive funding available through the IDeA program in the form of COBRE (Center for Biomedical Research Excellence) and INBRE (IDeA Networks of Biomedical Research Excellence) grants, and UND and NDSU anticipate submitting a joint proposal in fiscal year 2014 for a new INBRE grant.

At the University of North Dakota, we have been awarded funding for three phases of a COBRE grant supporting research on neurodegenerative diseases. We received funding for Phase III, the final phase of a COBRE project, during fiscal year 2013. North Dakota has one of the largest populations of the extremely old in the Nation (second only to Florida in the percentage of its citizens over 85 years of age), and high rates of neurodegenerative diseases such as Alzheimer’s, Parkinson’s, and multiple sclerosis. As an example of the impact of this funding and the research capacity it has built, externally funded research at the University of North Dakota’s School of Medicine and Health Sciences (SMHS) has grown substantially. Prior to COBRE funding, in fiscal year 2002, the SMHS received about \$12 million in external funding; by fiscal year 2011, this had increased to \$20.5 million, an increase of 71 percent. In 2010, when UND developed a new strategic plan for research, neuroscience was identified as an existing strength on which to build.

Thus, the neurobiology COBRE grant is achieving its intended purpose of expanding our research capacity and our ability to compete for Federal funding. That research is directed at problems of direct interest to our citizenry, but also to the rest of the United States.

The University of North Dakota has submitted a proposal for an additional COBRE grant on the topic of epigenetics. Epigenetics is the study of how environmental factors influence the expression of our genes; in many cases these changes in gene expression can then be inherited by the next generation. We have been notified that the submitted grant is a highly competitive one that addresses a burgeoning area of research interest and importance. Despite this, fiscal year 2013 funding cuts and further reductions due to the sequester mean it is unlikely that the grant will be funded.

North Dakota State University has received COBRE grants to fund research at its Center for Protease Research and the Center for Visual and Cognitive Neuroscience. COBRE funding supported important chemical and biological research at the Center for Protease Research relating to the roles played by enzymes that break down proteins in cancer and asthma.

COBRE funding at NDSU’s Center for Visual and Cognitive Neuroscience facilitated research illuminating and ameliorating conditions such as disordered perception, cognition, emotion, attention and executive function, which are hallmarks of debilitating and costly disease syndromes (e.g., ADHD, ARMD, agnosia, amblyopia, autism, depression, dementia, dyslexia, hemi neglect, multiple sclerosis, Parkinson’s disease, PTSD, and schizophrenia).

COBRE funding has contributed to the success that both NDSU's Centers have achieved in obtaining competitive grants from private sources and a variety of Federal agencies. Additionally, the COBRE grants led to the publication of NDSU's research findings in international, refereed publications and have aided in the recruitment of new faculty and increased enrollments in related graduate and undergraduate programs.

Another important IDeA program is INBRE, which provides funding to build the biomedical workforce through activities ranging from outreach to elementary school children to creating opportunities for undergraduates to engage in research. This program has provided support for undergraduate students at two- and four-year colleges in North Dakota to participate in research during the summer at their home institutions. This program includes two tribal colleges and serves between 70 and 100 students each year. Another program at the University of North Dakota serves about 60 undergraduates per year and applications routinely exceed the number of slots that are available. These programs are essential for keeping students in the pipeline for the STEM (science, technology, engineering, and math) workforce. Studies have repeatedly shown that engaging undergraduates in original research is a powerful tool for retaining students in college so that they graduate in a timely way.

A major emphasis has been on outreach programs to Native American students, the minority group that is most under-represented in the fields of science, engineering, and math. Between 25 and 35 Native American students in grades 7–12 participate each year in a program that uses traditional Native American tools to teach science. As many as 40 students from tribal colleges are funded each year to visit UND and learn about opportunities to transfer to the University and complete their four-year degrees. INBRE provides support for transfer students from tribal colleges through the Pathway program, a six-week summer program that prepares participants for advanced coursework in science. Pathway students can also receive tuition waivers from the University. INBRE funding is also provided to support the American Indian Health Research Forum on the UND campus each year; this forum attracts attendees from across the Nation.

North Dakota, with a population of 672,591 according to the 2010 Census, is the smallest of all the IDeA States. Yet, our School of Medicine and Health Sciences graduates a disproportionately large number of primary care physicians who practice in rural areas, and 20 percent of all Native American physicians in the U.S. are graduates of the University of North Dakota. This medical school is clearly making important contributions to health care for underserved populations. Like all medical schools, it must have a healthy research program underpinning its training of physicians, and funding from the IDeA program is critical to the health of that program and to building research capacity for the future.

The IDeA States produce STEM graduates at the same per capita rate as States with larger populations and larger research portfolios. The students from IDeA States need and deserve the same exposure to research as students in larger States. If the proposed reductions in the President's fiscal year 2014 budget request for the IDeA program are not rejected, North Dakota and other small, mostly rural States, will receive a major setback in their efforts to increase their capacity to undertake biomedical research and to train the next generation of scientists who are vital to the health of our Nation and economy.

The IDeA program is absolutely critical not only for the University of North Dakota and North Dakota State University, but also for the biomedical research capacity and capability of research institutions nationwide. We sincerely appreciate the subcommittee's ongoing support of the IDeA program and request that you give full consideration to our recommendations and fiscal year 2014 request of no less than \$310.0 million for the National Institutes of Health IDeA program. We further request that the subcommittee consider legislative language directing that future NIH budgets include funding for the IDeA program that reaches no less than 1 percent of the total NIH budget.

PREPARED STATEMENT OF THE WORLD MOLECULAR IMAGING SOCIETY

The World Molecular Imaging Society (WMIS) is dedicated to developing and promoting all aspects of preclinical and clinical multimodal medical molecular imaging to understand and effectively treat life-threatening oncological, neurological, cardiovascular, inflammatory, metabolic, infectious and other diseases. The WMIS is gravely concerned with the continued negative impacts to the U.S. research enterprise resulting from the significant decline in research funding, particularly due to sequestration coming on the heels of years of flat-funding. A higher level of research in medical molecular imaging is required in the U.S. to increase our knowledge

about disease processes, disease detection, and therapy management, with the long-term goal of improving the health of U.S. citizens that will provide savings of billions of dollars.

The U.S. has, until now, been the leading force in medical molecular imaging. Molecular imaging plays a central role in health care as it significantly contributes to improved patient outcome and cost-efficient healthcare in all major diseases. This high-impact field is finding transformative applications in the understanding, detection, and treatment of nearly all diseases. However, the impetus of this multidisciplinary transformative field is under severe threat due to declining funding that is impacting the U.S. economy in multiple ways:

- Rapid erosion of an exceptional workforce of highly trained molecular imaging scientists that represent the culmination of significant monetary and intellectual investments, often supported in part by public grants, aid, etc. The opportunity cost of their departure, therefore, is a profound;
- Decline of the U.S. as the world-leader in medical molecular imaging sciences, and the emergence of China and other nations as leaders in this field;
- Exploitation of U.S. intellectual property in medical molecular imaging by nations with little or no research enterprise, effectively discouraging complementary private research investment in the U.S.;
- Falling attendance at scientific conferences directly impacting local economies in host cities in the U.S., and undermining the interactions among scientists from diverse fields, at all stages of their careers (including students and young faculty), cutting short the next round of game-changing technologies and innovations; and
- Decreased market and student confidence in science-related fields and infrastructure—entire industries that support the scientific and imaging infrastructure are on the decline resulting in major loss of jobs and trainees.

Molecular imaging is truly a poster child for the success of the U.S.'s long history of investments in research. It represents a confluence of hard sciences and life sciences; medicine, physics, chemistry, computer science and anatomy. Out of decades of advances in each of these fields, molecular imaging is changing the way medicine is practiced, and it is just scratching the surface. Our field owns a generous global competitive advantage in this area—one that promises not just clinical impact but commercial as well. However, we cannot continue to see our seed funding for research dry up, and our scientists take their knowledge abroad. Other countries are waiting and willing to reap the benefits—both public and private—that we've already expended to bring us to this exciting point in scientific discovery. We cannot lose it.

Because of this, the WMIS strongly supports an increase in the NIH budget by at least 3 percent in fiscal year 2014. We also offer a plea to Appropriators to join with their colleagues in the Senate to replace the harmful sequester with a policy that does not seek to balance the budget on the backs of productive discretionary programs like medical research and science—which have remained essentially flat in nominal dollars for the past decade.